

ORGAN HARVESTS FROM THE LEGALLY INCOMPETENT: AN ARGUMENT AGAINST COMPELLED ALTRUISM

Abstract: *Organ transplants may offer the best hope of long term survival for individuals afflicted with certain cancers or other debilitating diseases. The hope that a transplant may inspire in an organ recipient should not, however, be the determinative factor when the proposed source of the organ is incompetent. Competent adults are not compelled to act altruistically by undergoing a surgical invasion for the benefit of third parties. Children and mentally incompetent adults should likewise be protected from such compelled altruism. Case by case adjudication of petitions to harvest organs from incompetents are inevitably driven by a concern for the recipient and an unwarranted deference to parental authority, and not by concerns for the autonomy and well being of the incompetent donor. This Note argues that organ harvests from legal incompetents should be statutorily prohibited.*

INTRODUCTION

It is axiomatic that advances in medical science which hold the promise of resolving questions of life and death tend to create ethical dilemmas of right and wrong.¹ Organ transplants are one such advance. An organ transplant often offers the best hope of long term survival from certain cancers and other debilitating diseases.² But that best hope cannot be realized unless a close, genetically matched organ can be quickly obtained. There are two sources of organs: those that are donated and those that are harvested. Organs are "donated" by competent adults who voluntarily and altruistically consent to give what is sometimes called, "the greatest gift."³ Organs are "harvested" from cadavers or living related children and mentally disabled adults—individuals who are unable to give a competent, valid con-

¹ See, e.g., B.D. Colen, *Whatever Happened to Baby Jane Doe? And Other Cases Involving Reproductive Ethics*, in HASTINGS CENTER REPORT 2 (1994).

² See Deane L. Wolcott et al., *Psychiatric Aspects of Bone Marrow Transplantation: A Review and Current Issues*, 4 PSYCHIATRIC MED. 299, 299 (1987) [hereinafter *BMT Review*].

³ See Hal Daniel Friedman, *The Greatest Gift, But At What Cost?—Objections to Court-Compelled Organ Donation In Aid of a Family Member*, 30 J. FAM. L. 605, 620 (1991-92) [hereinafter *Greatest Gift*]; *infra* notes 98-110 and accompanying text.

sent.⁴ It is this latter method of obtaining organs that poses the ethical dilemma: may the altruistic gift of an organ be compelled from a legal incompetent?⁵ Absent exigent circumstances, medical personnel must obtain parental or guardian consent before providing necessary medical treatment to children and mentally disabled adults.⁶ The requirement that parental consent be obtained is based on the principle that children and mentally disabled adults lack the maturity or ability to understand the consequences of accepting or foregoing treatment.⁷ Parental consent is considered sufficient to authorize necessary medical treatment on the grounds that parents are in the best position to determine and act on behalf of their children's best interests.⁸ For those same reasons, when medical treatment is unnecessary, but will improve the health of the child or mentally disabled adult, parental consent is again both necessary and sufficient.⁹

The sufficiency of a parent or guardian's consent is less clear, however, when the treatment is medically unnecessary and the beneficiary of the treatment is a third party¹⁰—such is the case when a

⁴ See Daniel B. Griffith, *The Best Interest Standard: A Comparison of the State's Parens Patria Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients*, 7 ISSUES L. & MED. 283, 308 (1991) (stating: "A person cannot make an informed decision if she lacks the capacity to reason and make judgments, her decision is not voluntary, and she lacks a clear understanding of the risks and benefits of alternatives as well as the nature and prognosis of the disease").

⁵ See *id.*

⁶ Physicians may treat children without parental consent if there is a risk to life or limb. See W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 18, at 117 & n.37 (5th ed. 1984). Furthermore, the state's interest in protecting the public health and welfare may override the need for parental consent. See, e.g., *Jacobsen v. Massachusetts*, 197 U.S. 11, 30 (1905) (upholding constitutionality of compulsory vaccines).

⁷ See *Little v. Little*, 576 S.W.2d 493, 495 (Tex. App. 1979, writ denied); Griffith, *supra* note 4, at 308; cf. *Bach v. Long Island Jewish Hosp.*, 267 N.Y.S.2d 289, 290-91 (N.Y. Sup. Ct. 1966) (holding that the consent of a minor emancipated by marriage was sufficient to authorize medically unnecessary treatment).

⁸ See Charles H. Baron, *Live Organ and Tissue Transplants from Minor Donors in Massachusetts*, 55 B.U. L. REV. 159, 165 (1975). Although the parental right to direct a child's upbringing has been recognized as a fundamental right, the state may, under its *parens patriae* power, burden that right or terminate parental rights altogether. See, e.g., *In re Tabatha R. v. Ronda R.*, 587 N.W.2d 109, 115, 119 (Neb. 1998) (upholding an order removing a child from the care of the parents when one parent was incarcerated and the other was in an institution for the criminally insane). See also *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) (overriding guardian's decisions regarding a minor's religious upbringing); *Sherr v. Northport*, 672 F. Supp. 81, 96 (E.D.N.Y. 1987) (overriding parents' objections to compulsory immunizations for their school-age child).

⁹ See William J. Curran, *A Problem of Consent: Kidney Transplantation in Minors*, 34 N.Y.U. L. REV. 891, 892 (1959).

¹⁰ See *Hart v. Brown*, 289 A.2d 386, 387 (Conn. Super. Ct. 1972) (physician and hospital refused to transplant a kidney from a seven year-old to her twin sister without a court

parent or guardian wishes to harvest an organ from a child or ward to save a sibling.¹¹ In this context, the interests of the incompetent no longer drive the medical treatment.¹² Rather, the incompetent's interests must be reconciled with or subsumed beneath the family and doctor's understandable desire to save the sibling.¹³ Yet, despite the absence of medical necessity or medical benefit, when confronted with petitions to harvest organs from incompetents, courts generally retreat behind presumptions of parental beneficence and give these procedures the blessing of judicial approval.¹⁴

In contrast, competent adults are under no compulsion to submit to organ harvests for the benefit of third parties.¹⁵ Adults may decline to be tested for initial compatibility, and if compatible, may stop the process at any time.¹⁶ Both the common law doctrine of informed

order declaring that the parents had the right to consent on the child donor's behalf); Curran, *supra* note 9, at 892; Jennifer K. Robbenmolt et al., *Advancing the Rights of Children and Adolescents to be Altruistic: Bone Marrow Donation by Minors*, 9 J.L. & HEALTH 213, 216-17 (1994-95).

¹¹ See Joel D. Kallich & Jon F. Merz, *The Transplant Imperative: Protecting Living Donors from the Pressure to Donate*, 20 J. CORP. L. 139, 143 (1995) (stating that "[u]nlike medical care provided to improve the health of a patient, organ donation provides no therapeutic benefit to the organ donor"); *Good Samaritan Hosp. v. Ohio Dept. of Health*, 642 N.E.2d 1160, 1162 n.2 (Ohio Ct. App. 1994) (noting that "bone marrow is an organ"). This Note only specifically addresses bone marrow and kidney harvests, but the argument applies to other organ harvests as well.

¹² See Curran, *supra* note 9, at 892.

¹³ See Little, 576 S.W.2d at 499; Janet L. Dolgin, *The Fate of Childhood: Legal Models of Children and the Parent-Child Relationship*, 61 ALB. L. REV. 345, 393 (1997); cf. Curran v. Bosze, 566 N.E.2d 1319, 1344-45 (Ill. 1990).

¹⁴ See Little, 576 S.W.2d at 497 (citing John A. Robertson, *Organ Donation by Incompetents and the Substituted Judgment Doctrine*, 76 COLUM. L. REV. 48, 53 (1976)) (stating: "Judicial approval for intra-family transplants from incompetent donors has been granted in most cases.").

¹⁵ See generally *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (1978) (refusing to compel a competent adult to undergo a bone marrow transplant for the benefit of his cousin).

¹⁶ See ROBERTA G. SIMMONS ET AL., *GIFT OF LIFE: THE SOCIAL AND PSYCHOLOGICAL IMPACT OF ORGAN TRANSPLANTATION* 289 (1977) [hereinafter *GIFT OF LIFE*] (noting the case of a daughter who backed out the night before she was to donate a kidney to her mother). See generally Lanie Friedman Ross et al., *Ethics of a Paired-Kidney-Exchange Program*, 337 NEW ENG. J. MED. 1392, (1997), available at <<http://www.nejm.org/content/1997/0336/0024/1752.asp>>. Friedman Ross et al. advocate a kidney exchange program that addresses the problem of adult donors withdrawing their consent at the last minute. Under this model, an individual who is willing to donate a kidney but who is a poor tissue match for his or her ill recipient would be paired with a second mismatched pair and the kidneys would essentially be bartered between them: willing Donor A would provide a kidney to Recipient B, and willing Donor B would provide a kidney to Recipient A. The proponents warn, however, that the transplants would have to take place simultaneously to eliminate the possibility that Donor B might withdraw her consent after Donor A had already undergone surgery. See *id.*

consent and the rejection of a general duty to rescue support the competent adult's decision to assist or ignore the needs of third parties.¹⁷ Similarly, competent adults may prohibit post-mortem harvests of their organs by making those wishes known by an advance directive.¹⁸

Society has long accepted and expected that in certain contexts the law will treat the legally competent differently from the legally incompetent.¹⁹ Contract and labor laws, for example, prevent the latter group from forming contracts or working in particular industries.²⁰ These distinctions are justified, in part, by society's interest in protecting those who are unable to protect themselves because of age or mental infirmity.²¹ Nevertheless, when courts and legislatures rush to defend legally competent donors from compelled harvests but defer to third-party interests when faced with legally incompetent donors, the differences take on a disturbing texture.²²

¹⁷ See, e.g., *Head v. Colloton*, 331 N.W.2d 870, 876 (Iowa 1983) (refusing to disclose identity of a potential bone marrow donor in a hospital donor registry to an individual suffering from leukemia); *McFall*, 10 Pa. D. & C.3d at 91; see also *Greatest Gift*, *supra* note 3, at 620 (arguing that even in the limited contexts in which states have found a duty to rescue, no legislature has gone so far as to require that the rescuer put him or herself at risk). But see Fordham E. Huffman, Comment, *Coerced Donation of Body Tissue: Can We Live with McFall v. Shimp?* 40 OHIO ST. L.J. 409, 414-22 (1979) (articulating four criteria which, if satisfied, would permit a patient to obtain a court order requiring an unwilling donor to undergo an organ harvest under threat of civil and criminal penalties).

¹⁸ See Aaron Spital, *Mandated Choice for Organ Donation: Time to Give it a Try*, 125 ANNALS INTERNAL MED. 66 (1996), available at <<http://www.acponline.org/journals/annals/>>, under Past Issues (noting that a Gallup poll confirmed the general sense that the individual, not the family, should make the decision about post-mortem organ donations, and further, that the family should not be able to override advance directives); cf. *Perry v. Saint Francis Hosp. & Med. Ctr.*, 886 F. Supp. 1551, 1561-62 (D. Kan. 1995) (finding that the use of deception to obtain a family's consent to extensive post-mortem donation was sufficiently outrageous to support a claim for intentional infliction of emotional distress).

¹⁹ See generally *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261 (1990) (O'Connor, J., concurring) (noting that it may be necessary for states to adopt special procedures in order to protect the liberty interests of incompetent patients); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977) (holding that it is the manner in which the state preserves and upholds the rights, rather than the substance of those rights, that distinguishes an incompetent from a competent individual).

²⁰ See 29 C.F.R. § 570.2 (1998) (child labor regulations); RESTATEMENT (SECOND) OF CONTRACTS § 12(2)(b), (c) (1979).

²¹ See *Saikewicz*, 370 N.E.2d at 428 (stating: "The 'best interests' of an incompetent person are not necessarily served by imposing on such persons results not mandated as to competent persons similarly situated. . . . To protect the incompetent person within its power, the State must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons.").

²² See *Strunk v. Strunk*, 445 S.W.2d 145, 146 (Ky. 1969); *McFall*, 10 Pa. D. & C.3d at 91; Louise Harmon, *Falling Off The Vine: Legal Fictions and the Doctrine of Substituted Judgment*,

This Note will argue that organ harvests from children and mentally disabled adults should be categorically prohibited.²³ Case-by-case adjudications of petitions to harvest organs from these individuals inevitably turn on a balance of the relative benefits and harms arising from organ transplants.²⁴ The cost-benefit analysis is flawed for two reasons.²⁵ First, courts refuse such a balance of benefits and harms when asked to compel competent adults to donate organs.²⁶ Second, the information on which the cost-benefit analysis is based is both incomplete and incorrect.²⁷ Moreover, using the most vulnerable members of society to shield us from the pain of a loved one's illness or imminent death is unfair.²⁸ It forces the child or mentally disabled adult to take on life and death burdens for which they are wholly unprepared and exposes them to harms from which they are wholly unprotected.²⁹ Only legislation which requires that individuals be fully competent to give an informed, meaningful consent before being candidates for live organ donations can alleviate the inherent dangers of adjudicating these issues case-by-case.³⁰

Part I of this Note provides an overview of organ transplantation and discusses the psychological effects and family dynamics that color the experience of donors and recipients. This foundation is necessary to critically examine the speculative psychological benefits courts rely on when they authorize organ harvests from children and the mentally disabled.³¹ Part II surveys the major case law in this area and notes a recent case which goes beyond the mere authorization to har-

100 YALE L.J. 1, 57 (1990) (tracing the history of the "legal fiction" and noting that its development in the "law of lunacy" permitted judges to be less protective of the property and bodies of incompetents without changing the underlying laws which so fiercely protected the property and bodies of competent individuals).

²³ See *infra* notes 327-43 and accompanying text.

²⁴ See *Curran*, 566 N.E.2d at 1344-45. See generally *Strunk*, 445 S.W.2d at 145; *In re Doe*, 481 N.Y.S.2d 932 (N.Y. App. Div. 1984) (per curiam).

²⁵ See *Curran*, 566 N.E.2d at 1344-45. See generally *Strunk*, 445 S.W.2d 145; *Doe*, 481 N.Y.S.2d 932.

²⁶ See *McFall*, 10 Pa. D. & C.3d at 91; *infra* notes 197-213 and accompanying text.

²⁷ See *infra* notes 236-73 and accompanying text.

²⁸ See *infra* notes 233-69 and accompanying text.

²⁹ See *infra* notes 253-69 and accompanying text. See generally *Dolgin*, *supra* note 13 (arguing that children suffer from the loss of childhood when shouldered with the burdens and privileges of adulthood).

³⁰ Cf. *Kallich & Merz*, *supra* note 11, at 150 (noting that prisoners are not permitted to donate organs because of the potential for coercion and abuse). See generally *Carl H. Fellner & John R. Marshall, Kidney Donors—The Myth of Informed Consent*, 126 AM. J. PSYCHIATRY 1245 (1970).

³¹ See generally *Strunk*, 445 S.W.2d 145; *Doe*, 481 N.Y.S.2d 932; *Little*, 576 S.W.2d 493.

vest an organ and actually discusses the recognition of a right to another's organ.³² Part II also examines the legal standards to which courts explicitly turn when deciding the cases. Finally, Part III analyzes the cost-benefit analysis underlying the court decisions that have authorized organ harvest petitions in light of the research presented in Part I. Part III then discusses why the judicial standards are unworkable and suggests legislative action as the way to ensure uniform and proper outcomes.

I. BACKGROUND

A. *Procedures and Effects of Bone Marrow and Kidney Transplants*

When faced with a child in need of an organ, parents and doctors often look to siblings because they tend to be more suitable donors than other family members or unrelated donors.³³ Sometimes, desperate parents will even conceive additional children solely to provide the older sibling with a donor.³⁴ As Part II will show, it is settled that a court has no authority to compel a competent adult to donate an organ.³⁵ In contrast, courts adopt a posture deferential to the needs of

³² See *Ferrell v. Rosenbaum*, 691 A.2d 641, 646 (D.C. 1997), discussed *infra* notes 215-31 and accompanying text.

³³ There is a 25% chance that a sibling will be a bone marrow match. See *Ferrell v. Rosenbaum*, 691 A.2d 641, 652 (D.C. 1997). Bone marrow transplants are used to treat aplastic anemia and some forms of leukemia and severe immunodeficiency diseases, although the therapy may offer no long-term advantages over conventional chemotherapy for patients with leukemia. See *BMT Review*, *supra* note 2, at 299. In 1984, approximately 450 bone marrow transplants were performed on children. See Deane L. Wolcott et al., *Psychological Adjustment of Adult Bone Marrow Transplant Donors Whose Recipient Survives*, 41 *TRANSPLANTATION* 484, 484 (1986) [hereinafter *BMT Donors*]. In 1997, the number was up to 2000. See Corinna Kaarela, *After a Child Donates Bone Marrow to a Sibling, Self-Esteem Often Fares Worse Than That of Non-Donor Brothers and Sisters*, UCSF PRESS RELEASE, Aug. 8, 1997, (visited Jan. 9, 2000) <<http://www.ucsf.edu/pressrel/pr0897/0808bone.html>>.

³⁴ See JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 213-14 (1994) [hereinafter *CHILDREN OF CHOICE*]; Gina Kolata, *Birth to Save Sibling Spurs Ethics Debate*, CHI. TRIB., June 4, 1991, at A1; Marissa Ayala: *Bonded by Bone Marrow, Two Sisters Live Happily Ever After*, PEOPLE, Mar. 15-22, 1999, at 78. [hereinafter *Marissa Ayala*].

³⁵ See *McFall v. Shimp*, 10 Pa. D. & C.3d 90, 91 (1978); see also *Head v. Colloton*, 331 N.W.2d 870, 872-73 (Iowa 1983) (refusing to disclose the identity of a matched donor who refused to donate bone marrow, despite the petitioner's grave medical condition); *In re George*, 630 S.W.2d 614, 622 (Mo. Ct. App. 1982) (refusing to open adoption records for an individual in need of a bone marrow transplant). But see *Huffman*, *supra* note 17, at 414-15 (suggesting a "construct" by which plaintiffs who satisfy certain criteria may obtain a court order and compel a reluctant donor to cooperate under threat of civil and criminal penalties).

third parties when the organ source is not legally competent, and they generally find authority to permit such harvests.³⁶ The emerging rationale among opinions authorizing harvests and commentators supporting the practice is that organ harvests psychologically benefit the volunteered donor.³⁷ These opinions argue that permitting the harvest ensures the child or mentally disabled individual's psychological well-being by preventing the death of a sibling and by conferring on him or her the benefits associated with altruistic acts.³⁸

Setting aside the question of whether speculative psychological benefits constitute a sufficient justification for this sort of bodily intrusion, these rationales assume away several important questions which this Note will attempt to answer:³⁹ (1) Are different transplant procedures sufficiently similar to warrant generalizing the experience of one type of donor to another?;⁴⁰ (2) Is the child or mentally disabled adult protected from psychological harm when his or her sibling survives?;⁴¹ and (3) Can data regarding the experience of adults who volunteer to donate an organ reliably predict the experience of the child or mentally disabled adult who is volunteered?⁴²

1. Different Transplant Procedures Yield Different Results

There are two obvious differences between a bone marrow and a kidney transplant: First, bone marrow regenerates while a kidney does not; and second, whereas bone marrow is extracted through a thick needle, making it seem analogous to the common experience of donating blood, a kidney transplant requires major surgery.⁴³ These do

³⁶ See *Hart v. Brown*, 289 A.2d 386, 387 (Conn. Super. Ct. 1972) (regarding kidney harvest from seven year-old twin); *In re Doe*, 481 N.Y.S.2d 932, 933 (N.Y. App. Div. 1984) (per curiam) (regarding bone marrow harvest from mentally retarded adult); *Little v. Little*, 576 S.W.2d 493, 497 (Tex. App. 1979, writ denied) (regarding kidney harvest from young girl with Down's Syndrome).

³⁷ See Rachel M. Dufault, *Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211, 230 (1991); Robbenmolt, *supra* note 10, at 214.

³⁸ See Dufault, *supra* note 37, at 230; Robbenmolt, *supra* note 10, at 214.

³⁹ See generally Baron, *supra* note 8; Robertson, *supra* note 14.

⁴⁰ See *infra* notes 43-58 and accompanying text.

⁴¹ See *infra* notes 59-94 and accompanying text.

⁴² See *infra* notes 98-126 and accompanying text.

⁴³ See *BMT Review*, *supra* note 2, at 300. After undergoing tissue typing, a bone marrow harvest must be done under general anesthesia so the marrow can be extracted via multiple punctures in the pelvic area with a rigid needle screwed through the bone. See *id.* It takes approximately half an hour and upwards of 200 taps to extract one liter of bone marrow fluid from an adult; the procedure must be repeated at various intervals to extract sufficient bone marrow fluid from a child. See Baron, *supra* note 8, at 163 n.20; Diane M.

not, however, constitute the only differences between the two types of transplants.⁴⁴ The other perhaps more significant differences have less to do with the manner in which the organ is harvested and more to do with the underlying disease which has created the need for the organ in the first place.⁴⁵ These differences, in turn, materially affect the experience of the donor.

The time frame in which a family must locate a suitable donor and the post-transplant prognosis for the organ recipient, are two such factors that differ dramatically depending on the nature of the disease and that can seriously and adversely affect the donor.⁴⁶ In terms of the timing of the transplant, options short of a kidney transplant from a living related donor exist for most people in need of a kidney.⁴⁷ Dialysis, for example, can sustain an individual with no functioning kidney for upwards of twenty-five years, depending on the nature and severity of the underlying disease.⁴⁸ Organs from cadavers have become more available as awareness about the great need for organs and comfort with the idea of donating has grown.⁴⁹ Emotion-

Gianelli, *Bearing a Donor? Ethical Concerns Raised Over Having Baby for Marrow Match*, AM. MED. NEWS 3, available in 1990 WL 3259464. Although the greatest physical risk is from the anesthesia, infection is also a concern. See Gianelli, *supra*; Celia Hall, *Donor's Operation Carries Little Risk*, DAILY TELEGRAPH, Apr. 19, 1997, at 3.

Renal transplants are significantly more involved. Donors tend to experience a great deal of pain and discomfort post-transplant and there is a 28.2% risk of complications, ranging from mild infections and lung problems to extreme cases in which the donor contracts the same illness which afflicted the recipient. See GIFT OF LIFE, *supra* note 16, at 166. Major complications include damage to the spleen or adrenal glands, major bleeding and pulmonary embolisms. See Kallich & Merz, *supra* note 11, at 147. In addition, both donors and recipients have a permanent scar running from mid-abdomen to mid-back. See GIFT OF LIFE, *supra* note 16, at 166.

⁴⁴ See BMT Donors, *supra* note 33, at 484-85, 487.

⁴⁵ See *id.*

⁴⁶ See *id.*

⁴⁷ See, e.g., Richard L. Faber, *Twenty-Five Years on Dialysis*, in THE KIDNEY PATIENT HANDBOOK ch. 6-b, (Richard L. Faber & Stephen W. Wilde eds., 4th ed. 1993) available at <<http://www.ultranet.com/~ktida/>>. Faber's essay, begun in 1972, recounts his twenty-five year experience with dialysis treatment, his return to normal functioning and the ongoing health problems caused by his underlying kidney disease. See generally *id.*

⁴⁸ See *id.*

⁴⁹ Between 1990 and 1995 the number of cadaveric kidneys available in the United States rose from 9878 to 11,818, a small but not insignificant increase. See Laura G. Dooley & Robert S. Gaston, *Stumbling Toward Equity: The Role of Government in Kidney Transplantation*, 1998 U. ILL. L. REV. 703, 721 n.98. But see Kallich & Merz, *supra* note 11, at 142-43 (noting that the low rate of increase in the number of available cadaveric kidneys can likely be traced to a decrease in the number of automobile fatalities and an increase in diseases such as HIV that preclude transplantation). Authors Kallich & Merz conclude that the pressures on living donors will increase as the supply of cadaveric organs becomes insufficient to meet the demand. See *id.*

ally related donors, such as spouses and friends, are also becoming more acceptable sources of kidneys.⁵⁰ Until recently, doctors were reluctant to mine this particular source of organs because of compatibility concerns; however, developments in immunosuppressive pharmacology have reduced the need for the type of close genetic match that was formerly thought necessary.⁵¹ These options materially affect the experience of the donor by reducing the pressure a family may feel to come up with an immediate donor, and by easing the psychological pressure on the individual family member that he or she is the patient's only hope.⁵²

A bone marrow transplant, on the other hand, may be the patient's best hope for survival.⁵³ Furthermore, the window of opportunity for performing a bone marrow transplant is generally quite

⁵⁰ See Jeff Punch, *Spouses as Kidney Donors: Recent Findings and Statistics*, (visited Jan. 9, 2000) <<http://www.transweb.org/qa/asktw/answers/answers9507/Spousalkidneydonors.html>>. The life expectancy for recipients of kidneys from emotionally related donors closely approximates the life expectancy for recipients of parent or cadaver kidneys. See *id.*

⁵¹ See *id.* In particular, the introduction of the immunosuppressive Cyclosporine can be credited with widening the set of kidney donors. See *id.*; Kallich & Merz, *supra* note 11, at 140-41. But see Hart, 289 A.2d at 389 (listing the serious and permanent side-effects associated with immunosuppressives).

⁵² *BMT Donors*, *supra* note 33, at 484-85. This is not to suggest that these options are optimal. Dialysis is a demanding treatment and patients often find the treatment and its strict regimen of food, medication and exercise physically and emotionally draining. See generally *PSYCHONEPHROLOGY I: PSYCHOLOGICAL FACTORS IN HEMODIALYSIS AND TRANSPLANTATION* (Norman B. Levy ed., 1981) [*hereinafter* *PSYCHONEPHROLOGY*].

⁵³ See *BMT Review*, *supra* note 2, at 299. The efficacy of the treatment depends on the underlying disease. See *id.* While a bone marrow transplant may be the optimal treatment for some individuals with aplastic anemia, leukemia patients may fare no better from a bone marrow transplant than from the regular course of chemotherapy. See *id.* Advances in medical science may eventually provide alternatives to current practices. For example, transplants between individuals who are not closely matched may become more feasible, umbilical cord blood may provide a source of bone marrow, and cloning whole organs may become possible. See, e.g., Andrew Skolnick, *Application Considered for Immunotoxin in Treatment of Graft-vs-Host Disease*, 265 JAMA 2041, 2042 (1991) (stating that new drug shows promise in reducing graft-versus-host disease (GVHD) for patients receiving bone marrow transplants from their parents); Richard Saltus, *Report Offers Vision of Versatile Fix-it Cell*, BOSTON GLOBE, Nov. 6, 1998, at A3 (reporting that scientists isolate human cells with the potential to develop into any kind of cell in the human body, and that "stem cells," which are only present "in the first few days of embryonic life," can reproduce in a petri dish). Autologous transplants, the removal (prior to chemotherapy) and subsequent reinfusion (after chemotherapy) of the patient's own bone marrow are being used for certain types of cancers, but other types continue to require allogenic transplants, that is, bone marrow from a donor. See *Dexter v. Kirschner*, 984 F.2d 979, 981, 987 (9th Cir. 1992) (rejecting claim that under the Equal Protection Clause of the Fourteenth Amendment the state Medicaid system was required to fund both allogenic and autologous bone marrow transplants).

small.⁵⁴ The urgency of the situation makes it more likely that a bone marrow donor, unlike a kidney donor, will feel that the life or death of the ill family member is in his or her hands.⁵⁵ For children and mentally disabled adults, the urgency has the added effect of encouraging hasty court proceedings with little adversarial content.⁵⁶ Moreover, a failed bone marrow transplant exacts a higher price than a failed kidney transplant because death from the complications associated with a bone marrow transplant tends to be more agonizing than death from the underlying disease.⁵⁷ The fact that kidney and bone marrow transplants may yield vastly different results is a critical difference between the two types of transplants because, as discussed in the next section, the psychological well-being of the donor is often tightly bound to the ongoing health and well-being of the recipient.⁵⁸

2. The Potential for Psychological Harm from Donating an Organ

Courts that have authorized organ harvests have assumed a cause and effect relationship between a transplant and the prevention of psychological harm.⁵⁹ In other words, courts assume that permitting the transplant will ensure the survival of the sibling, which in turn will

⁵⁴ See Baron, *supra* note 8, at 182 (noting that the urgency of the situation results in the adult donor being pressured to make an immediate decision while for the incompetent donor, the situation results in a rushed legal proceeding in which the donor's interests go unprotected). *But cf. Doe*, 481 N.Y.S.2d at 932-33 (granting petition to harvest bone marrow from severely retarded adult notwithstanding the fact that the life of the ill sibling, also an adult, was not in immediate jeopardy).

⁵⁵ See *BMT Donors*, *supra* note 33, at 484-85.

⁵⁶ See Baron, *supra* note 8, at 181-88. Professor Baron notes that many guardians ad litem assigned by Massachusetts courts to represent the volunteered donors were actually doctors who worked for the hospitals at which the transplants were to be performed. *See id.* at 184. In addition to concerns about conflicts of interest, doctors may be better equipped to be information resources than vigorous advocates for the interests of young or incompetent donors. *See id.*

⁵⁷ *See id.* at 163 n.19; Deane L. Wolcott et al., *Adaptation of Adult Bone Marrow Transplant Recipient Long-Term Survivors*, 41 *TRANSPLANTATION* 478, 484-85 (1986) [hereinafter *BMT Recipients*]; *see also* *Newmark v. Williams*, 588 A.2d 1108, 1117-18 (Del. 1990) (upholding parents' right to refuse aggressive cancer treatment for their young son). In *Newmark*, the court found that the treatment was "the most aggressive form of cancer therapy short of a bone marrow transplant." *Id.* at 1118. If the treatment itself did not kill the boy, it would offer him a forty-percent chance of survival, measured not in terms of cure, but in terms of living for two additional years, cancer free. *See id.* at 1119 n.12.

⁵⁸ *See generally BMT Donors*, *supra* note 33.

⁵⁹ *See, e.g., Hart*, 289 A.2d at 389; *Doe*, 481 N.Y.S.2d at 933; *Little*, 576 S.W.2d at 499; *cf. Curran v. Bosze*, 566 N.E.2d 1319, 1343-44 (Ill. 1990) (refusing to authorize a bone marrow transplant where the sibling relationship was too tenuous to support a finding of psychological benefit).

protect the child or mentally disabled donor from psychological harm, or alternatively, will provide the donor with a psychological benefit.⁶⁰ Undoubtedly, some transplants do achieve their purposes with no measurable ill effects on the donor.⁶¹ Research indicates, however, that this best outcome may be far less common than people realize.⁶²

Transplant operations often create a unique link between the donor of an organ and its recipient.⁶³ Sometimes, this link opens the door to greater closeness and a sense of mutual support.⁶⁴ The link, however, also tends to bind the pair in such a way that the donor's psychological well-being and the quality of the donor-recipient relationship becomes dependent on the recipient's health and well-being.⁶⁵ One team of researchers at the University of California, Los Angeles (UCLA) studied these various effects.⁶⁶ In one study, the UCLA researchers found a high, direct correlation between a recipient's perception of his or her health, social functioning and overall well-being and the donor's perception of their relationship.⁶⁷ They suggested that "physical or psychosocial deterioration in [bone marrow transplant] recipients may result in significant psychological distress in the donor."⁶⁸

Unfortunately, significant physical or psychosocial "deterioration" is common among bone marrow recipients because bone marrow transplants involve a high risk of severe, short-term illness and an of-

⁶⁰ See *Hart*, 289 A.2d at 389; *Doe*, 481 N.Y.S.2d at 933; *Little*, 576 S.W.2d at 499; cf. *Curran*, 566 N.E.2d at 1343-44.

⁶¹ See *BMT Donors*, *supra* note 33, at 487.

⁶² See *id.* at 485. Wolcott et al. noted that little attention has been paid to the long-term psychological adjustment of bone marrow donors because, overall, kidney donors seem to adjust quite well. In other words, researchers have wrongly assumed that the experience of one set of donors can accurately predict the experience of another set of donors. See *id.* at 484; *BMT Recipients*, *supra* note 57, at 478.

⁶³ See *BMT Donors*, *supra* note 33, at 487. See generally Roberta Simmons, *Psychological Reactions to Gift Giving*, in *PSYCHONEPHROLOGY*, *supra* note 52, at 227.

⁶⁴ See *Marissa Ayala*, *supra* note 34, at 78.

⁶⁵ See *BMT Donors*, *supra* note 33, at 487; Simmons, *supra* note 63, at 234.

⁶⁶ See generally *BMT Donors*, *supra* note 33; *BMT Recipients*, *supra* note 57; *BMT Review*, *supra* note 2.

⁶⁷ See *BMT Donors*, *supra* note 33, at 487. In addition, the passage of time post-transplant did not diminish the correlation between the recipient's wellness and the donor-recipient relationship. See *id.* A sister who donated a kidney to her brother reported that he had been avoiding her for three months following the operation. "I was never so crushed. I would call him up and he would be as cold as ice. I was destroyed. To this day I don't mention the kidney in front of him. . . . He has never come out and said 'Thank you.'" Simmons, *supra* note 63, at 234.

⁶⁸ *BMT Donors*, *supra* note 33, at 487.

ten low rate of long-term survival.⁶⁹ The statistics are grim: the one-year survival rate averages only fifty to sixty percent, and among those recipients who survive, approximately twenty-five percent experience significant health problems.⁷⁰ For many recipients, significant health problems manifest in the form of Graft Versus Host Disease (GVHD), a disease caused by the transplant itself.⁷¹ Bone marrow produces white blood cells; white cells form the core of our immune system. An essential result of a bone marrow transplant, therefore, is that the immune system of the donor is transplanted into the recipient:⁷²

[J]ust as a host's immune system will [treat] a transplanted liver or heart as foreign tissue and react against it, a transplanted immune system will [treat the] host's entire body as foreign tissue and react against it. . . . [A]cute GVHD manifests itself in one of three ways: a skin rash that can progress to blistering and ulceration, liver damage that can progress to liver failure, and damage to the intestinal lining that can lead to massive gastrointestinal bleeding. Chronic GVHD, which . . . can either follow an episode of acute GVHD or arise spontaneously, has symptoms that resemble those of autoimmune diseases like lupus and scleroderma, including severe rashes, thickening and scarring of the skin, and limitation of joint motion.⁷³

GVHD is the single greatest threat to a bone marrow recipient's health following a transplant.⁷⁴ In addition to the medical complications caused by GVHD, the drugs used to treat GVHD are strongly associated with a wide spectrum of psychiatric and physical syndromes, including renal failure, delirium, anorexia, chronic sleep

⁶⁹ See *id.*; see also *R. v. Cambridge Health Auth.*, 2 All E.R. 129, 133-35 (C.A. 1995) (upholding the Health Authority's refusal to fund a second bone marrow transplant where the treatment would only yield a 10% chance of survival if the treatment itself did not kill her); *BMT Recipients*, *supra* note 57, at 478, 480, 482.

⁷⁰ See *BMT Recipients*, *supra* note 57, at 478. Statistics can, of course, mean different things to different people, numbers which give a donor pause might well give a recipient hope. But lest the reader lose sight, the question is not whether a recipient may benefit from the transplant but whether the benefits courts impute to organ donors are likely to be realized.

⁷¹ See Ronald Kline, *New Marrow for Old*, MIT ALUMNI TECH. REV., Nov. 1993, at 43.

⁷² See *id.*

⁷³ *Id.*

⁷⁴ See *id.*

disorders and gonadal dysfunction.⁷⁵ Furthermore, even patients who suffer from no GVHD complications have shown neurological damage from the regular course of cancer treatment alone.⁷⁶ Although researchers continue to search for a way to prevent GVHD, one researcher noted that while GVHD often kills its victims, those who survive the most severe bouts of the syndrome seem to have a greater chance of long-term survival.⁷⁷

To date, only one study has focused particularly on the experience of minors from whom bone marrow was harvested for the benefit of a sibling.⁷⁸ Researchers at the University of California, San Francisco found that fully one-third of children whose siblings were bone marrow recipients suffered from signs of post traumatic stress syndrome, even if the transplant had taken place years earlier.⁷⁹ The children were depressed, complained of recurrent nightmares, had overdeveloped fears of hospitals and needles and had a constant sense of dread that the experience might be repeated.⁸⁰ This was true for both siblings who donated and siblings who did not donate.⁸¹ The sib-

⁷⁵ See *BMT Review*, *supra* note 2, at 305–06. Post-bone marrow transplant delirium led, in at least one reported case, to stupor and coma. See *id.*

⁷⁶ See *id.* at 305. Severe cognitive impairment and altered interpersonal behavior were observed in a small percentage of patients at the UCLA clinic where the transplants and subsequent studies were performed. See *id.*

⁷⁷ See generally Kline, *supra* note 71.

⁷⁸ See Kaarela, *supra* note 33.

⁷⁹ See *id.*; Philip Cohen, *Donor's Dread: Why do Children Who Help a Sick Sibling End Up Depressed?*, 155 *NEW SCIENTIST* 20, 20 (1997).

⁸⁰ See Cohen, *supra* note 79, at 20; Kaarela, *supra* note 33.

⁸¹ See Cohen, *supra* note 79, at 20; Kaarela, *supra* note 33. It should not come as a surprise that all of the siblings showed signs of trauma, regardless of whether they were selected to donate. Proponents of organ harvests from minors might use this fact to argue that because the whole family unit is traumatized by the illness visited on one of its members, the situation for the young donor is not made worse by his participation in the organ harvest. The UCSF study did not, however, control for the accumulated effects of the non-donors being eliminated from the harvesting procedure. It is very possible, therefore, that the trauma non-donors experience is as much a result of the donor selection process as it is a result of the illness itself. For example, the non-donor's trauma might be a consequence of the child's fear and worry of possibly being chosen and the guilt that attends his feelings of relief for having escaped selection. Additionally, the child may experience conflicted feelings of jealousy regarding the attention and praise the donor sibling receives and confusion about how to understand all of these feelings in the face of his sister or brother's struggle to live. See, e.g., Roger Dobson, *Your Sister Could Save Your Life. Luckily She Wants To*, *INDEF.* (LONDON), May 14, 1996, at 6.

Furthermore, the study may support an argument that the emotional cost of extraordinary medical treatments on individual family members and the family unit as a whole may, in some cases, outweigh the remote chance of a cure for the ill child. See generally George Howe Colt & Eugene Richards, *The American Family: Part Five: When a Child is Sick*, *LIFE*, Aug. 1991, at 58 (reporting one family's experience with childhood leukemia

lings who donated, however, were more withdrawn, anxious, depressed and had a lower sense of self-esteem, which the researchers attributed to a guilty fear that their tissue might not be "good enough."⁸² Other researchers have similarly warned that if the child turns out to be an incompatible donor or the transplant is unsuccessful, "[t]he . . . guilt which may follow in the wake of [that] failure could be transferred to the donor child with untoward effects, either in early bonding or later, as the child grows up under the shadow of having failed in an important task."⁸³ Moreover, negative reactions to these procedures are not restricted to young donors. Despite the fact that a bone marrow harvest is less complicated surgically, the percentage of adult bone marrow and kidney donors reporting negative reactions to the donation experience was roughly the same.⁸⁴ Nor are difficulties in the ongoing relationships between donors and recipients limited to those cases in which the recipient fared poorly or died.⁸⁵ Contrary to the expectation that a good medical result for the recipient will lead to a good psychological result for the donor and the relationship, some donor-recipient pairs become estranged even when the recipient is a long-term disease-free survivor.⁸⁶ This finding led the UCLA researchers to express concern that the approximately ten to twenty percent of the adult donors in one study who exhibited adverse psychological consequences was only the "tip of the iceberg," because those donor-recipient pairs who had become estranged declined to participate in the study at all.⁸⁷ Lastly, they cautioned that donors as a class may show a "relatively high incidence of pathological grief reactions" if their recipients do not survive.⁸⁸

and noting that the healthy sibling was withdrawn, angry and resentful, the father developed heart problems as a result of the stress and the mother, who worked two and sometimes three jobs to support the family, came home each night ragged and worn out).

⁸² See Cohen, *supra* note 79, at 20.

⁸³ Warren Kearney & Arthur L. Caplan, *Parity for the Donation of Bone Marrow: Ethical and Policy Considerations*, in 1 *EMERGING ISSUES IN BIOMEDICAL POLICY: AN ANNUAL REVIEW* 262, 275 (Robert H. Blank & Andrea L. Bonnicksen eds., 1992).

⁸⁴ See *GIFT OF LIFE*, *supra* note 16, at 154, 169; Kallich & Meiz, *supra* note 11, at 148 n.30.

⁸⁵ See *supra* note 62 and accompanying text; see also *BMT Donors*, *supra* note 33, at 487.

⁸⁶ See *BMT Donors*, *supra* note 33, at 487; see also *GIFT OF LIFE*, *supra* note 16, at 171-75. One author has noted that "[t]he donor who demonstrates clear ambivalence prior to donation is likely to find the recipient reacting with hostility rather than gratitude for the gift. The reluctant gift may be accepted, but the donor loses more than the gift in the exchange." *GIFT OF LIFE*, *supra* note 16, at 175.

⁸⁷ See *BMT Donors*, *supra* note 33, at 487.

⁸⁸ See *id.* at 488.

Kidney transplants similarly bind the fate and well-being of donors and recipients. While short-term health and long-term survival for the kidney recipient are decidedly better than for the bone marrow recipient, kidney recipients have exhibited disturbing psychological effects as a result of the transplant, and this in turn affects the donor and the donor-recipient relationship.⁸⁹ The psychological effects observed in kidney recipients include delusions that the transplant will lead to a full and complete recovery and a refusal to acknowledge the true risks involved. In addition, recipients may become depressed or suffer from the psychotic belief that they have taken on the qualities of the donor through the transplanted organ.⁹⁰ More commonly, kidney recipients manifest a chronic fear and worry that they are living on stolen time.⁹¹ Finally, recipients of kidneys donated by relatives have reported that they suffer from guilt and a sense of having an unpayable debt hanging over their heads, an emotional residue that is uncommon for individuals who receive kidneys from cadavers.⁹²

For the kidney donor, the physical toll of the harvesting procedure is much greater than that exacted on the bone marrow donor from the bone marrow extraction procedure. A kidney harvest involves major surgery and results in the permanent loss of an organ as well as a scar running from mid-back to mid-abdomen.⁹³ Moreover, because the rejection rate for even closely matched kidneys can run as high as twenty percent, kidney donors may experience not only a sympathetic or guilt reaction, but may feel that they underwent major surgery and gave up a kidney for nothing.⁹⁴

⁸⁹ See generally PSYCHONEPHROLOGY, *supra* note 52.

⁹⁰ See Pietro Castelnuovo-Tedesco, *Transplantation: Psychological Implications of Changes in Body Image*, in PSYCHONEPHROLOGY, *supra* note 52, at 219, 222; Jorge Steinberg et al., *Psychological Factors Affecting Acceptance or Rejection of Kidney Transplants*, in PSYCHONEPHROLOGY, *supra* note 52, at 185, 189.

⁹¹ See Castelnuovo-Tedesco, *supra* note 90, at 220-21. One researcher hypothesized that these psychological effects were peculiar to treatments which effectively extend rather than save a patient's life. See *id.* In other words, individuals who are treated by having diseased tissue or organ surgically removed are more likely to see their treatment as reclaiming their proper life span than are those whose treatment involves the receipt of another's tissue or organ. That no psychosis or delusions were reported among recipients of life-saving treatments is evidence for the researcher's hypothesis. See *id.*

⁹² See *id.*; GIFT OF LIFE, *supra* note 16, at 171-72.

⁹³ See GIFT OF LIFE, *supra* note 16, at 166.

⁹⁴ See *id.* at 169. In one study, the rejection rate for kidneys was 18% and a number of donors exhibited or reported having severe negative reactions to the news. See *id.* One brother who donated reported becoming hysterical when he found out that his kidney had been rejected, exclaiming: "What a waste for me and what a horrible thing for him." *Id.*

The physical and psychological differences between bone marrow and kidney transplants make it difficult to speak of organ transplants as an undistinguished class of procedures.⁹⁵ Differences in the underlying diseases and in the transplant procedures lead to different stresses and different types of risks. Similarly, the methods by which individuals become donors vary to such a degree that to speak of organ donors as an undistinguished class of individuals is misleading.⁹⁶ Just as the bone marrow donor may be more likely to experience psychological trauma than the kidney donor, the donor who is volunteered may be more likely to experience psychological or physical trauma than the donor who steps forward as a mature and competent volunteer.⁹⁷

B. *The Volunteer vs. the Volunteered*

Adults become live donors when they register with organ procurement organizations or agree to donate in response to a family member's acute need.⁹⁸ The context in which an adult donates and the factors leading to the decision to donate vary. In turn, context and motivating factors may determine the donor's experience of the donation itself.⁹⁹ The set of adult organ donors can therefore be broken down into three distinct groups: (1) the altruistic, anonymous adult donor; (2) the family member who decides to donate in response to internal pressures; and (3) the family member who decides to donate in response to external pressures.¹⁰⁰ Because minors and mentally disabled adults cannot volunteer but must be volunteered by parents or guardians, they make up a fourth, closed class of compelled donors.¹⁰¹

⁹⁵ See *supra* notes 43-58 and accompanying text.

⁹⁶ See *infra* notes 99-126 and accompanying text.

⁹⁷ See *infra* notes 99-126 and accompanying text.

⁹⁸ See generally Mark F. Anderson, *Encouraging Bone Marrow Transplants From Unrelated Donors: Some Proposed Solutions to a Pressing Social Problem*, 54 U. PITT. L. REV. 477 (1993); Kallich & Merz, *supra* note 11.

⁹⁹ See GIFT OF LIFE, *supra* note 16, at 165; Anderson, *supra* note 98, at 530 (noting that the donor who is "forced to undergo an operation that exposes her to a small but significant health risk as well as physical discomfort for several days . . . will likely suffer serious psychological trauma. . .").

¹⁰⁰ See GIFT OF LIFE, *supra* note 16, at 233-71; Anderson, *supra* note 98, at 487-88; Feller & Marshall, *supra* note 30, at 1250.

¹⁰¹ See generally Robert W. Griner, Note & Comment, *Live Organ Donations Between Siblings and the Best Interest Standard*, 10 GA. ST. U. L. REV. 589, 602-08 (1994).

Adults who decide to participate in organ procurement organizations do so voluntarily out of a sense of charity and social duty.¹⁰² These donors generally remain anonymous, as do the identities of the recipients.¹⁰³ Much has been written about the satisfaction and heightened self-esteem these donors experience when they learn that their organ or tissue may have given someone a fighting chance to survive.¹⁰⁴ It may be, however, that it is the anonymity and voluntariness peculiar to this type of organ donation that permits the donor to experience the euphoria of having done something utterly selfless and good.¹⁰⁵

Family members who decide to donate organs when illness strikes close to home fall into two primary groups: those who donate in response to a sense of moral obligation and those who donate in response to pressure from families or medical personnel.¹⁰⁶ Generally,

¹⁰² See Anderson, *supra* note 98, at 529. Additionally, an individual's willingness to donate at all may depend on the voluntariness of the donation process. Charitable organizations that attempt to coerce participation by pressuring volunteers or making them feel guilty, for example, are likely to see a reduction in their contributions. See Alan Radley & Marie Kennedy, *Charitable Giving by Individuals: A Study of Attitudes and Practices*, 48 HUM. REL. 685 (1995) (noting that when people experience charitable solicitations as intrusive, refusing to give becomes "an exercise of one's rights as a private citizen" rather than a "breach of a social norm").

¹⁰³ See *Head*, 331 N.W.2d at 872 (refusing to disclose identity of a potential bone marrow donor in a hospital donor registry to an individual suffering from leukemia). Although participants in bone marrow registries remain anonymous, if their bone marrow is used and the recipient survives the first year post-transplant, the donor and recipient's identities may be disclosed with both parties' consent. In some cases, a lasting relationship may develop between the formerly anonymous donor and the recipient of the tissue. The author of this Note had the opportunity to speak with one such donor about his experience. Mr. Nicholas Economou participated in a local bone marrow registry near his home in Virginia. His bone marrow ultimately went to a five year-old girl, Carly Scherer of Buffalo, New York, who was suffering from a rare form of leukemia. The transplant was performed in June 1995, Mr. Economou and Carly met in June 1996. Though separated by thousands of miles, the two families have since become very close. Carly will be declared cured in May 2000, an event in which both families will share. See Telephone Interviews with Nicholas Economou, November 1999-January 2000; see also Louise Continelli, *Girl Earns Place Among Young Cancer Survivors*, BUFFALO NEWS, Feb. 9, 2000, at 5B.

¹⁰⁴ See *Officer Is One In a Million*, HERALD (GLASGOW), Sept. 17 1998, at 12 (recounting the experience of a Scottish police officer whose participation in the UK bone marrow registry led to him becoming a donor). One donor has noted: "What could be more worthwhile than offering somebody the chance of life—it really is an amazing feeling." *Id.*

¹⁰⁵ See *id.* Moreover, the fact that such stories receive this type of media attention and public commendation indicates that these acts of altruism are considered acts of heroism.

¹⁰⁶ See *GIFT OF LIFE*, *supra* note 16, at 233–50; Simmons, *supra* note 63, at 230. Family members who donate also make up a third, middle group. This group arrives at the decision to donate after more deliberation than those who feel morally obligated. See *GIFT OF LIFE*, *supra* note 16, at 254–58. At the same time, for these donors family pressure plays an

when adults decide to donate in response to a sense of moral obligation—that is, on the basis of an internal motivation—they experience their participation as voluntary and generally feel good about their decision in both the short-term and the long-term.¹⁰⁷ While the ill family member's need for the organ triggers the donor's feeling of moral obligation, the donation itself is driven by the need to satisfy the feeling of obligation.¹⁰⁸ The donor's participation does not, ultimately, depend on the outcome of the transplant nor the risks involved.¹⁰⁹ A clear and developed sense of one's moral obligation, therefore, seems to reduce the likelihood that a donor will be ambivalent about giving up the organ, and may in turn immunize him from the psychological after-effects noted above.¹¹⁰

The second group of family members decide to donate in response to pressure from family or from medical personnel.¹¹¹ This pressure can range from subtle situational pressures, to messages as blatant as: "if you don't donate, s/he will die."¹¹² Whereas moral obligation can properly be called an internal motivation, these pressures are external and can be quite intense.¹¹³ More than half of the kidney

identifiable, albeit a less coercive and corrosive, role. *See id.* at 257–58. For purposes of this analysis, the more extreme types of decision-making capture the key components of the more mediated decision-making process.

¹⁰⁷ *See* GIFT OF LIFE, *supra* note 16, at 165, 285.

¹⁰⁸ *See id.* at 238, 239–50.

¹⁰⁹ *See id.*

¹¹⁰ *See id.* at 165.

¹¹¹ *See* Kallich & Merz, *supra* note 11, at 144 (pressure from medical personnel); GIFT OF LIFE, *supra* note 16, at 154–65 (family pressure).

¹¹² *See* GIFT OF LIFE, *supra* note 16, at 165 (noting that 12% of the case studies involved "blatant unwelcome types of family pressure").

¹¹³ *See generally*, e.g., *Lawse v. University of Iowa Hosps.*, 434 N.W.2d 895 (Iowa Ct. App. 1988). In one case, a living kidney donor brought an action against the hospital and doctors for wrongful removal of his kidney. *See id.* at 896. Thirteen years after he donated a kidney to his brother, the donor's remaining kidney failed. *See id.* at 898. The donor claimed that because the hospital and staff had negligently failed to respond to his unwillingness to donate, his consent had been coerced. *See id.* The donor specifically alleged that the doctor and hospital had coerced him by giving him misinformation or insufficient information: (1) despite the fact that his brother was doing well on dialysis, he had been told that his brother would die without his kidney; (2) he was counseled that "there was basically no risk to him, it was like having an appendix removed" and (3) information about his tissue typing had been shared with other family members before he had been informed of the results—information that could not help but affect those members' willingness to donate. At the same time, information about another brother's refusal to donate was kept from him. *See id.* at 897. The court frankly discussed the coercive effect of family pressure and aired the concern that as a result, related donors may never be able to give a truly informed consent. *See id.* The case was dismissed, however, because the statute of limitations had run out. *See id.* at 898.

donors in one study group were subject to pressure that researchers felt had a "compulsory quality."¹¹⁴ Even when the pressure is not overt, the threat of family sanctions may be coercive to the point where family members feel that they truly have no choice.¹¹⁵ The face of death, however, only rarely changes existing and entrenched family dynamics.¹¹⁶ A hard but undeniable truth is that family members may not be loved or valued equally.¹¹⁷ Sibling rivalry, favoritism and other pre-illness conflicts affect the way families manage the stress of the illness, as well as the process by which donors may be selected.¹¹⁸ Moreover, these factors color the long term experience of the donor and may even affect the medical success of the transplant.¹¹⁹

¹¹⁴ See *GIFT OF LIFE*, *supra* note 16, at 160–61. Fifty-four percent of the donors in the study group were subject to such "compulsory" pressures. *See id.* at 161.

¹¹⁵ See Kallich & Merz, *supra* note 11, at 144–46. One author has noted: "The social mores of the family [may] dictate that all members . . . offer to donate their organs. . . . Violating this norm entails substantial and likely penalties that few would endure willingly, such as excommunication from the entire family unit." *Id.* at 146. One mother spoke about the pressure on her ten-year-old daughter to donate:

In a way, I suppose, she didn't really have a choice. We simply told her the facts. We didn't say, "Look if you don't do it, Lewis will die," because that would have been too much, but she knew as much. At the end of the day a parent isn't going to say, "The choice is yours. If you decide not to, that's fine, we'll just prepare for our son's funeral." If she had had very strong views against being a donor, I don't know what we would have done.

Dobson, *supra* note 81. In fact, the ten year-old daughter had hoped she would not turn out to be a match and spoke of her fear of hospitals and needles. *See id.* None of this, however, amounted to the daughter holding "strong views" in the mother's eyes. *See id.*

¹¹⁶ See Baron, *supra* note 8, at 173; Fellner & Marshall, *supra* note 30, at 1248.

¹¹⁷ See *BMT Donors*, *supra* note 33, at 487. "[O]ne mother remarked openly to [the transplant team] . . . 'Isn't it strange that it ends up our [son, the] black sheep . . . is the donor to our favorite [daughter].'" *See id.* This comment led to staff aptly to ask, "What will these parents do to this donor son psychologically if she dies?" *See id.*

¹¹⁸ *See id.*; *see also* Baron, *supra* note 8, at 173 (noting the danger that parents will be "particularly insensitive" to the harm a "disfavored donor" might suffer or "particularly impressed" with the benefits a "favored recipient" might receive).

¹¹⁹ See *GIFT OF LIFE*, *supra* note 16, at 445; *see also* Castelnovo-Tedesco, *supra* note 90, at 222–23 (reporting the case of a boy who made a suicidal gesture, rejected the grafted kidney and died after discovering that the kidney had been donated by his "ne'er do well" father); Steinberg, *supra* note 90, at 189. Steinberg attempted to predict the acceptance or rejection of transplanted kidneys on psychological factors alone. *See id.* at 186–87. Of the twenty-six recipients in the study, only one was rated as "unlikely" to retain the transplanted kidney. *See id.* at 188–89. In that case, a forty-eight year-old aunt agreed to donate a kidney to her ill and estranged twenty-six year-old niece. *See id.* The family urged the aunt to be the donor because of their belief that the operation would reunite the two women. *See id.* Notwithstanding her aunt's willingness to donate, however, the niece maintained her distance. *See id.* This reaction angered the aunt, and prompted the aunt to tell her niece to "[t]ake my fucking kidney. . . [.] I don't want to see you again." *See* Steinberg,

Notwithstanding the internal and external pressures on family members to volunteer, adults may decide that for whatever reason, they are unwilling to step forward.¹²⁰ Among the immediate family, studies have found that adult siblings of ill family members are the least willing to donate while parents and children are the most willing.¹²¹ Nor is it uncommon for an adult family member to publicly manifest a willingness to be a donor but, in the privacy of a medical consultation, indicate by actions or words that he or she does not actually wish to donate.¹²² In response, medical personnel have been known to manufacture medical excuses that provide unwilling donors a graceful way out and that protect them from further family pressure.¹²³

Minors and mentally disabled adults make up the final set of donors, but rather than volunteering to donate, these donors are volunteered by a parent or guardian.¹²⁴ The question for medical personnel, then, turns not on the child or mentally disabled adult's willingness to donate, but on the parent or guardian's legal authority to consent to the donation on behalf of the child or ward.¹²⁵ This is the way that judges and courts most commonly become involved in the process of obtaining organs from live donors.

supra note 90, at 189. As predicted, the aunt's kidney was rejected shortly after the transplant. *See id.*

¹²⁰ *See* Simmons, *supra* note 63, at 228 (forty-three percent of family members declined to be tested for initial compatibility); *see also* Friedman Ross, *supra* note 16 (expressing the concern that an organ exchange program which effectively eliminates the "incompatible donor" excuse may be problematic for those donors who count on being able to express their show of support for the family member without being under any obligation to donate).

¹²¹ *See* GIFT OF LIFE, *supra* note 16, at 203-04. The percentages of family members who donated or volunteered to donate were: parents (86%); adult children (66%); sisters (48%) and brothers (46%). *See id.* at 203. Despite their relative unwillingness to donate, most related organs come from siblings. *See id.* at 204.

¹²² *See* GIFT OF LIFE, *supra* note 16, at 289; Fellner & Marshall, *supra* note 30, at 1246; Kallich & Merz, *supra* note 11, at 152.

¹²³ *See* GIFT OF LIFE, *supra* note 16, at 212, 289; Fellner & Marshall, *supra* note 30, at 1246. *But see* Kallich & Merz, *supra* note 11, at 144-45 (noting that although most pressure can be traced to the family, transplant teams sometimes become so invested in the survival of a patient that they ignore a potential donor's worries or reluctance to donate).

¹²⁴ *See generally* Hart, 289 A.2d 386; Little, 576 S.W.2d 493.

¹²⁵ *See* Leonard H. Glantz, *Law, Medicine and Socially Responsible Research*, 24 AM. J.L. & MED. 213, 220 (1998). *See generally* Hart, 289 A.2d 386; Little, 576 S.W.2d 493; Baron, *supra* note 8.

II. CASE LAW AND THE APPLICABLE LEGAL STANDARDS

Uncertainty about a parent or guardian's right to consent to medically unnecessary organ harvests from children and mentally disabled adults has led doctors and hospitals to require court orders to preempt any question of liability.¹²⁶ State courts are the current forum for adjudicating such petitions.¹²⁷ There are currently no statutes authorizing or compelling organ harvests from compatible incompetents.¹²⁸ In their absence, courts have historically applied the "best interest" or "substituted judgment" standard.¹²⁹ Regardless of which standard is applied, a cost-benefit analysis underlies most judicial reasoning, balancing the benevolent desire of the family to save the life of an ill family member against the known physical risks and theoretical psychological benefits that might accrue to the organ donor.¹³⁰

A. *The Standards and Analyses Courts Apply to Incompetent Donors*

The judicial standards to which courts turn when faced with a petition to harvest organs from legal incompetents have roots that pre-date the organ procurement dilemma by hundreds of years.¹³¹ The best interest standard, for example, can be traced back to the

¹²⁶ See, e.g., Glantz, *supra* note 125, at 220-24; cf. Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941) (holding that a fifteen-year-old's consent was invalid to authorize a physician to perform a skin graft on him for the benefit of his cousin, but indicating, in dicta, that the parents' consent would likely have been sufficient). See generally Baron, *supra* note 8.

¹²⁷ See generally, e.g., Curran v. Bosze, 566 N.E.2d 1319 (Ill. 1990); Little v. Little, 576 S.W.2d 493 (Tex. App. 1979, writ denied).

¹²⁸ See Curran, *supra* note 9, at 892; Baron, *supra* note 8, at 177. Professor Baron noted in his 1975 article that at that time there was one state statute that permitted 14-year-olds to consent to donate organs, but that statute has since been repealed. See *id.* Currently, the only statutes governing organ harvests involve post-mortem harvests. See, e.g., David A. Jeffries, Note, *The Body as Commodity: The Use of Markets to Cure the Organ Deficit*, 5 IND. J. GLOBAL LEGAL STUD. 621, 631 (1998) (noting that all fifty states and the District of Columbia adopted the 1968 Uniform Anatomical Gift Act and its 1987 revisions, designed to encourage organ donation and provide guidelines for organ procurement efforts). At least two commentators, however, have advocated some form of legislation which would mandate either participation in donor registries or the actual donation. See generally Anderson, *supra* note 98 (mandatory participation in bone marrow registries with voluntary donation); Huffinan, *supra* note 17 (compulsory donation under threat of civil and criminal penalties).

¹²⁹ See, e.g., Hart v. Brown, 289 A.2d 386, 390-91 (Conn. Super. Ct. 1972) (applying substituted judgment standard to authorize a kidney transplant from a minor); *In re Doe*, 481 N.Y.S.2d 932, 933 (N.Y. App. Div. 1984) (per curiam) (applying best interest standard to authorize a bone marrow harvest from a mentally retarded adult).

¹³⁰ See Hart, 289 A.2d at 390-91; *Doe*, 481 N.Y.S.2d at 933.

¹³¹ See Dolgin, *supra* note 13, at 361.

dramatic social, philosophical and economic shifts of the 18th and 19th centuries, which in turn led to changes in the way that children were perceived and the way that childhood was understood.¹³² Where children were once treated as simply small adults, the view emerged that children should be safeguarded from many of the ills of adulthood and an increasingly industrialized society.¹³³ The best interest standard developed as a way for the legal system to accommodate this emerging view and today it remains the governing principle for adjudicating civil cases involving minors.¹³⁴ Courts generally invoke this standard under the *parens patriae* power of the state—the state's responsibility and authority to protect society's most vulnerable members.¹³⁵

The substituted judgment doctrine, on the other hand, was originally applied in cases involving the property or estate of a now incompetent but formerly competent individual.¹³⁶ In its present form, the standard requires that decisions be made *not* by substituting a court or guardian's values, but rather in accordance with the values or wishes the individual expressed while still competent.¹³⁷ Whereas

¹³² See *id.* The evolution of a child-centered approach in custody disputes, for example, can be traced from the early view that fathers had an absolute right to custody, to the presumption that the mother was the proper custodian, to the recent, more flexible, best interest standard that permits a court of equity to consider the individual circumstances. See Griffith, *supra* note 4, at 292.

¹³³ See Dolgin, *supra* note 13, at 360–61.

¹³⁴ See *id.* at 361. See generally Curran, 566 N.E.2d at 1319 (holding that the best interest standard was the proper one for evaluating petitions to harvest organs from minors and mental incompetents).

¹³⁵ See Griffith, *supra* note 4, at 305, 331; see also Doe, 481 N.Y.S.2d at 932.

¹³⁶ The substituted judgment doctrine can be traced back to the English case *Ex parte Whitbread*, 35 Eng. Rep. 878 (Ch. 1816) and the English law of lunacy. See Harmon, *supra* note 22, at 19. The chancellor in that case was faced with the niece of a lunatic (someone who had once been of sound mind and who might regain his sanity) who pleaded that she needed a greater apportionment of her uncle's money. See *id.* at 20. Rather than try to gain some insight into this particular lunatic's situation or his relationship with this particular relative, the chancellor instead relied on what the objective, "reasonable lunatic" would wish to do under the circumstances. See *id.* at 22. Because the *Whitbread* decision was about "remedy[ing] an inconvenience . . . that might result from the general rule of law" without disturbing accepted and established allocations of rights and property, Harmon contends that the substituted judgment doctrine constituted a legal fiction from its very inception. See *id.* at 7, 22–23; Lynn E. Lebit, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgments Doctrine*, 7 J.L. & HEALTH 107, 108 (1992–93). The doctrine has been recognized in American courts since 1844, but only since *Strunk v. Strunk* has it been extended to medical decisions involving individuals who were never of sound mind. See Harmon, *supra* note 22, at 32.

¹³⁷ Cf. *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261, 336 (1990) (Stevens, J., dissenting). The expectation is that the substitute decisionmaker will have sufficient information or insight into the proclivities of the individual or situation to make a decision which closely approximates the decision the individual would make for himself if he were

the best interest standard might properly be described as paternalistic, the substituted judgement standard, in theory, protects the individual's right to make decisions for him or herself.¹³⁸ The doctrine has since grown beyond its roots in property law to encompass non-therapeutic medical decisions made on behalf of incompetents.¹³⁹ Furthermore, the doctrine has been applied to individuals who were never legally competent, a practice which exposes the values of the true decisionmaker: the court or guardian.¹⁴⁰

A survey of reported cases helps to establish the outer limits to which courts will go to find authorization for an organ harvest and to highlight the judicial reasoning that supports imposing a global prohibition on harvests from minors and mentally disabled adults.¹⁴¹

1. Substituted Judgment Standard Applied

In 1969, the Kentucky Court of Appeals decided *Strunk v. Strunk*, the first reported organ transplant case.¹⁴² *Strunk* expanded the scope of the substituted judgment doctrine, holding that a mother's consent was sufficient to authorize the removal of one of her mentally retarded son's kidneys.¹⁴³ The recipient, Tommy, was twenty-eight years old and suffering from a fatal kidney disease; the donor, Jerry, was twenty-seven years old, with a mental age of six.¹⁴⁴ Each member of the family was tested for compatibility, but Jerry was the only potential match.¹⁴⁵ In order to reach its holding that the substituted judgement

able. See *id.* Griffith argues that the usefulness of the standard diminishes as evidence of past preferences becomes less reliable and that where the evidence is *unreliable*, the standard constitutes a legal fiction. See Griffith, *supra* note 4, at 303.

¹³⁸ See Griffith, *supra* note 4, at 318–23.

¹³⁹ See generally *Strunk*, 445 S.W.2d 145; Robertson, *supra* note 14.

¹⁴⁰ See *Strunk*, 445 S.W.2d at 146; Harmon, *supra* note 22, at 34–35 (criticizing *Strunk* for eliminating the protection the original standard provided to incompetent individuals). See generally Lebit, *supra* note 136.

¹⁴¹ Many cases go unreported. For a sample of Massachusetts slip opinions authorizing harvests, see Baron, *supra* note 8, at 161–62 nn.15–16.

¹⁴² 445 S.W.2d 145. Although *Strunk* was the first reported transplant case, there were a substantial number of unreported cases dating back to 1957. See Baron, *supra* note 8, at 161–62 nn.15–16 (discussing twenty-two unreported cases out of the Massachusetts courts, including the first petition brought before any court; in every case, courts of equity were found to have the power to authorize organ transplants between minor siblings).

Strunk remains the most frequently cited organ transplant case and has sparked a great deal of debate. Most commentators and courts have concluded that the *Strunk* court arrived at the proper decision but applied an improper standard.

¹⁴³ See *Strunk*, 445 S.W.2d at 149.

¹⁴⁴ See *id.* at 145–46. Jerry was permanently institutionalized. See *id.* at 146.

¹⁴⁵ See *id.*

standard was the correct standard to apply, the *Strunk* court analogized the transfer of an incompetent's organ to the transfer of an incompetent's real or personal property.¹⁴⁶ *Strunk* is widely recognized as the first United States case to extend this doctrine beyond questions of property to medical decisions made on behalf of an incompetent when the incompetent's own health was not threatened. *Strunk* also extended the doctrine to situations involving individuals who had no history of ever having been legally competent.¹⁴⁷

Strunk set the unfortunate precedent of invoking the substituted judgment doctrine while relying on a determination that the transplant was in the incompetent brother's best interest, a determination that was framed in terms of a cost-benefit analysis.¹⁴⁸ Finding that the benefit (saving his brother) outweighed the cost (losing his kidney), the court reasoned that the transplant was in Jerry's best interest, and therefore, within the power of the court to authorize.¹⁴⁹

The *Strunk* dissent, however, noted that the extension of the substituted judgment doctrine to medically unnecessary procedures was not only without precedent, but inconsistent with existing state case law and contrary to the scope of existing state statutes.¹⁵⁰ Additionally, although sympathetic to the terrible choices facing the family, the dissent voiced the concern that taking a body part from one who could not fully understand or consent brought to mind the types of human experiments conducted during World War II.¹⁵¹

After *Strunk*, courts were divided regarding the proper scope and application of the substituted judgment doctrine.¹⁵² Some courts rejected *Strunk's* reasoning; others embraced and extended it.¹⁵³ In 1972, in *Hart v. Brown*, the Connecticut Superior Court followed in *Strunk's* footsteps by holding that a court of equity had the power to authorize a kidney transplant from a seven year-old to her twin sis-

¹⁴⁶ See *id.* at 148.

¹⁴⁷ See *id.* at 148; Harmon, *supra* note 22, at 34-35.

¹⁴⁸ See *Strunk*, 445 S.W.2d at 148.

¹⁴⁹ See *id.* at 150 (Steinfeld, J., dissenting).

¹⁵⁰ See *id.* at 149-50.

¹⁵¹ See *id.* at 149. The *Strunk* dissent stated: "[T]o hold that committees, guardians or courts have such awesome power [to remove a kidney from a mentally incompetent individual for transplant purposes] even in the persuasive case before us, could establish legal precedent, the dire result of which we cannot fathom. Regretfully I must say no." *Id.* at 151.

¹⁵² See, e.g., *Hart*, 289 A.2d 386; *In re Richardson*, 284 So. 2d 185 (La. Ct. App. 1973); *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975).

¹⁵³ See generally *Hart*, 289 A.2d 386; *Richardson*, 284 So. 2d 185; *Pescinski*, 226 N.W.2d 180.

ter.¹⁵⁴ *Hart* similarly relied on the substituted judgment doctrine for its equity powers, but engaged in a cost-benefit analysis to determine whether or not the transplant was in the child-donor's best interests.¹⁵⁵

Transplants between identical twins enjoy the greatest long-term success, because the genetic similarities reduce the possibility that the organ will be rejected.¹⁵⁶ A transplant from any other individual requires that the recipient be given immunosuppressive drugs to inhibit the body's natural defenses.¹⁵⁷ Suppressing the immune system puts the recipient at risk of infection and other diseases, and the drugs themselves have well-documented short and long-term side effects.¹⁵⁸ The *Hart* decision turned almost exclusively on the severity of potential complications the recipient twin might endure if a kidney other than her identical twin's were used.¹⁵⁹ The court went so far as to characterize any outcome that would require resort to immunosuppressive drugs as "cruel and inhuman."¹⁶⁰ As a "close, independent and objective" investigation of [the parents'] motivation" indicated that the decision was morally sound in the eyes of the community, the court held that permitting the parents to substitute their consent for the consent of their minor child was the only just result.¹⁶¹

2. The Best Interest of the Child Standard and the Interests of Third Parties

A few years after *Strunk* was decided, two courts explicitly rejected its extension of the substituted judgment doctrine to petitions involving organ harvests from individuals who have never been competent. Instead, the courts applied the best interest standard.¹⁶² Both the Lou-

¹⁵⁴ 289 A.2d 386.

¹⁵⁵ *Id.* at 389-90.

¹⁵⁶ *See id.* at 388.

¹⁵⁷ *See id.* at 389.

¹⁵⁸ *See id.* (stating: "The side effects of the immunosuppressive drug . . . are numerous and include the possibility of bone marrow toxicity, liver damage, and a syndrome called Cushing syndrome—a roundish face, a 'buffalo hump' on the back of the neck, and growth retardation. Some less common side effects are a demineralization of the bone mass which will result in the collapsing of bones of the spine; aseptic necrosis of the femoral head of the hip, making a person unable to walk; peptic ulcer disease with bleeding; hairiness; sexual immaturity; and cataracts of the eyes.").

¹⁵⁹ *See Hart*, 289 A.2d at 389.

¹⁶⁰ *See id.* at 391.

¹⁶¹ *See id.* at 389-90. The court recounted the testimony of the Hart family's clergyman and the guardian ad litem who all agreed that the transplant should go forward. *See id.*

¹⁶² *See Richardson*, 284 So. 2d at 187; *Pescinski*, 226 N.W.2d at 182.

isiana Court of Appeals, in *In re Richardson*, and the Wisconsin Supreme Court, in *In re Pescinski*, denied the guardians' petitions to authorize kidney harvests from incompetent siblings.¹⁶³ These courts reasoned that when a transplant is for the sole benefit of a third party, it is, by definition, not in the best interest of the incompetent individual.¹⁶⁴

Pescinski and *Richardson* distinguished *Strunk*, noting that guardianship laws in neither state could support the procedural or substantive posture of that decision.¹⁶⁵ Rather, the laws in both states empowered guardians merely to protect the estate of an incompetent, not to make independent decisions regarding the disposition or betterment of the estate.¹⁶⁶ The *Pescinski* and *Richardson* courts reasoned that such unqualified protection of a property right could not be greater than the protection of a minor or incompetent's "right to be free from bodily intrusion."¹⁶⁷ *Richardson* held that because the organ harvest was for the sole benefit of the older sibling, the transplant was not in the best interest of the retarded brother and therefore, the court denied the petition.¹⁶⁸ The *Pescinski* court denied the petition on similar grounds: holding that absent the consent of the incompetent individual, neither the court nor the guardian had the authority to consent to an organ transplant that would benefit only a third party.¹⁶⁹

The *Pescinski* dissent sharply criticized the majority for its unwillingness to adopt the substituted judgment doctrine.¹⁷⁰ The dissenting judge reasoned that where an individual is incompetent and unable to speak for himself, it is appropriate for a court of equity to substitute its own judgment and do for the incompetent what the court is certain the incompetent would do for himself if he were able.¹⁷¹ In the

¹⁶³ See *Richardson*, 284 So. 2d at 187; *Pescinski*, 226 N.W.2d at 182.

¹⁶⁴ In *Richardson*, the potential donor was a seventeen year-old retarded boy who had a mental age of about three; the average life expectancy for his type of retardation was only twenty-five years. The recipient was his thirty-two year-old sister. See *Richardson*, 284 So. 2d at 186. In *Pescinski*, the potential donor was a thirty-nine year-old catatonic schizophrenic. The recipient was his thirty-eight year-old sister who had been on dialysis for five years. See *Pescinski*, 226 N.W.2d at 180-81.

¹⁶⁵ See *Richardson*, 284 So. 2d at 187; see also *Pescinski*, 226 N.W.2d at 182.

¹⁶⁶ See *Richardson*, 284 So. 2d at 187; see also *Pescinski*, 226 N.W.2d at 182.

¹⁶⁷ See *Richardson*, 284 So. 2d at 187; see also *Pescinski*, 226 N.W.2d at 183 n.1 (Day, J., dissenting) (noting that the majority analogized permitting the kidney harvest to giving away the incompetent's property).

¹⁶⁸ See *Richardson*, 284 So. 2d at 187.

¹⁶⁹ See *Pescinski*, 226 N.W.2d at 181, 182.

¹⁷⁰ See *id.* at 182 (Day, J., dissenting).

¹⁷¹ See *id.* at 184.

dissent's view, the substituted judgment standard weighs the harms and benefits that might accrue to both siblings from prohibiting or permitting the transplant.¹⁷² The dissent argued that in this case, prohibiting the transplant harmed the incompetent brother because it condemned him to be forever "a receiver, a taker, but never a giver."¹⁷³ The *Pescinski* and *Richardson* majorities, on the other hand, refrained from balancing harms and benefits.¹⁷⁴ Rather, once the courts found that no benefit would flow to the incompetent donors, the courts' analysis was complete.

Courts that adopted *Strunk's* explicit substituted judgment reasoning, however, still adhered to its underlying best interests analysis. In 1984, in *In re Doe*, the New York Supreme Court, Appellate Division, affirmed the trial court's order authorizing a bone marrow transplant from a forty-three year-old severely retarded adult to his thirty-six year-old leukemic brother.¹⁷⁵ As the source of the court's power to authorize the transplant was grounded in its *parens patriae* power, the court held that it could only authorize such a transplant if it found the transplant to be in the incompetent's best interests.¹⁷⁶ In determining the best interests of the incompetent donor, the trial court did the same type of cost-benefit analysis that the *Strunk* court used and that the *Pescinski* dissent advocated, finding that the possible death of the leukemic brother outweighed the possible physiological and psychological harm from the harvest itself.¹⁷⁷

In 1990, in *Curran v. Bosze*, the Supreme Court of Illinois denied a petition to harvest bone marrow from minor twins, and in so doing, dealt directly with the differences between the substituted judgment and best interest standards.¹⁷⁸ The father brought a petition on behalf of his twelve year-old son in order to compel the mother of his three year-old illegitimate twins to have them tested for compatibility.¹⁷⁹ The

¹⁷² See *id.* at 183.

¹⁷³ See *id.* at 184. In holding that the court could only authorize action that would benefit the incompetent financially or physically, the dissent argued, the incompetent "is forever excluded from doing the decent thing, the charitable thing." *Id.*

¹⁷⁴ See *Richardson*, 284 So. 2d at 187; *Pescinski*, 226 N.W.2d at 181.

¹⁷⁵ See *Doe*, 481 N.Y.S.2d at 933. The appellate decision is no more than a page long, with few facts and little analysis. The lower court's decision has been sealed, as are many such decisions. See, e.g., Baron, *supra* note 8, at nn.15 & 16.

¹⁷⁶ See *Doe*, 481 N.Y.S.2d at 932-33.

¹⁷⁷ See *id.* at 933.

¹⁷⁸ See 566 N.E.2d 1319; see also Lebit, *supra* note 136, at 108.

¹⁷⁹ See *Curran*, 566 N.E.2d at 1321. Both trial and appellate courts denied the father's request that the question of compelling compatibility testing be decided separately from the question of compelling the transplant itself. See *id.* at 1345. The legal strategy behind

facts showed that the twins' parents had never been married, the twins' paternity was established by a blood test shortly after birth and the siblings had met on only two occasions.¹⁸⁰

In its carefully drafted opinion, *Curran* rejected the use of the substituted judgement doctrine in adjudicating petitions involving minors and other individuals who had never been legally competent.¹⁸¹ The court reasoned that it is a competent adult's "philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death" to which he or she looks to make important decisions about submitting to or refusing medical treatment.¹⁸² Under *Curran*, where because of age or infirmity an individual has not developed a personal value system, application of the substituted judgment doctrine "undermin[es] the foundation of self-determination and inviolability of the person upon which the right to refuse medical treatment stands" because the decisionmaker must substitute his or her own values for those of the incompetent.¹⁸³ *Curran* held that the best interest standard was the proper one to apply in these situations and outlined three factors that courts should consider when determining whether a transplant is in the best interests of the child or ward: (1) the parent must be informed of the risks and benefits of the harvesting procedure; (2) the primary caretaker must be prepared to provide the donor with the necessary emotional support and (3) the relationship between the donor and recipient must be close.¹⁸⁴

In determining the best interests of the young twins, *Curran* heavily relied on testimony that the twins would suffer psychological harm,

the request is transparent: it would likely be more difficult for the mother or the court to resist the transplant if the twins were discovered to be perfect matches. See generally Anderson, *supra* note 98. In a similar vein, Anderson proposes a mandatory bone marrow registry with voluntary donation. See *id.* at 494-527. Leaving the actual donation to the discretion of the individual in the event he or she turns out to be a match, Anderson argues, would encourage donation without violating substantive due process or raising privacy concerns. See *id.* at 527 n.139. Nevertheless, Anderson's scheme relies on people being shamed or coerced into donating organs once the need for the bone marrow is particularized via a tissue match. See *id.* at 526.

¹⁸⁰ See *Curran*, 566 N.E.2d at 1320, 1321. The blood test took place in the context of a paternity suit filed by the mother against the father. See *id.* at 1320.

¹⁸¹ See *id.* at 1325-26; Lebit, *supra* note 136, at 108 (noting that "[t]he father argued that under the doctrine of substituted judgment, the children would agree to submit to the procedure if they were old enough to make an informed, rational decision.").

¹⁸² See *Curran*, 566 N.E.2d at 1323.

¹⁸³ See *id.* at 1324 (quoting *In re Estate of Longeway*, 549 N.E.2d 292, 299 (Ill. 1989)).

¹⁸⁴ See *id.* at 1325-26, 1343.

not from being compelled to donate bone marrow, but rather from undergoing the harvest without the support of their mother.¹⁸⁵ The court also relied on psychiatric testimony tending to show that no benefit could be attributed to the twins absent a close relationship with their half-brother.¹⁸⁶ Applying the best interests test, the *Curran* court found that both parents were well-informed about the risks and benefits of the procedure, but questioned the mother's ability to provide the necessary emotional support because of her objections to the transplant.¹⁸⁷ Furthermore, the court found that the relationship between the half-siblings went no deeper than their paternal blood ties.¹⁸⁸ Because two of the three factors were unsatisfied, the bone marrow transplant was not in the twins' best interests, and therefore the court denied the father's petition.¹⁸⁹

Whether courts follow *Strunk's* explicit application of the substituted judgment standard or its implicit search for the best interests of the child or ward, petitions to authorize organ harvests from incompetents have been decided on the basis of a cost-benefit analysis.¹⁹⁰ Some courts frame the equation exclusively in terms of harm to the donor: will the possible loss of a sibling cause more psychological or physical harm to the donor than the operation itself?¹⁹¹ Other courts have framed the analysis in terms of the benefits that they and the parents hope the incompetent will realize from his or her participation in the transplant.¹⁹² Some courts seek to balance the relative

¹⁸⁵ See *id.* at 1335.

¹⁸⁶ See *id.* at 1343-44.

¹⁸⁷ See *Curran*, 566 N.E.2d at 1344.

¹⁸⁸ See *id.* at 1344.

¹⁸⁹ See *id.*

¹⁹⁰ See *Lebit*, *supra* note 136, at 113. Professor Baron has noted that "[i]n effect, [the parents] are given the authority to sacrifice the interests of the prospective donor if they reasonably conclude that the costs to him are outweighed by the potential benefits to the recipient." Baron, *supra* note 8, at 172.

¹⁹¹ See *Strunk*, 445 S.W.2d at 146; *Doe*, 481 N.Y.S.2d at 932. Both the *Strunk* and *Doe* courts concluded that the psychological harm the incompetents might experience from the death of their sibling outweighed the physical risks of the harvesting procedures. See *Strunk*, 445 S.W.2d at 146; *Doe*, 481 N.Y.S.2d at 932.

¹⁹² See *Curran*, 566 N.E.2d at 1343-44. *Curran* held, for example, that in order to authorize an organ harvest, a court must find that the donor will benefit psychologically from the transplant and furthermore, that donors can only be expected to realize the psychological benefit when the donor has an existing relationship with their sibling-recipient. See *id.* *Richardson*, on the other hand, held that a court must find a more tangible benefit to the donor before it can authorize the harvest. See 284 So. 2d at 187. The *Richardson* court analogized an organ harvest to the transfer of property: if the transfer of the 'property' will not benefit the owner, then a guardian does not have the authority to give that 'property' away. See *id.*

harms to which donors and recipients will be subjected, or alternatively, the relative benefits donors and recipients will realize.¹⁹³

The benefits/harms approach is peculiar to petitions involving minors and mentally disabled adults. Petitions to compel competent adults to undergo medically unnecessary surgical procedures have yielded results similar to the *Richardson*, *Pescinski* and *Curran* line of cases, but the analysis has been markedly different.¹⁹⁴

B. *The Standards and Analyses Courts Apply to Competent Donors*

The detailed analyses courts use when deciding whether or not to permit an organ harvest from a minor or incompetent adult stand in striking contrast to the quick and sharply worded dismissal of a similar claim brought against a competent adult.¹⁹⁵ For example, in 1978, in *McFall v. Shimp*, the Pennsylvania District and County court held that a court of equity had no authority to compel a competent adult to submit to a bone marrow transplant.¹⁹⁶ The plaintiff in *McFall* suffered from a rare, and ultimately terminal, bone marrow disease. The defendant, his cousin, had undergone compatibility tests, and although he was a match, he declined to donate.¹⁹⁷ The court, in an opinionated and brief decision, took both parties to task.¹⁹⁸ Criticizing the plaintiff for advocating such a blatant violation of an individual's right to bodily integrity, the court warned, "[f]or a society which respects the rights of *one* individual, to sink its teeth into the jugular vein . . . of one of its members and suck from it sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence."¹⁹⁹ Notwith-

¹⁹³ The *Hart* court and the *Pescinski* dissent are typical of this approach. See *Hart*, 289 A.2d at 389-90; *Pescinski*, 226 N.W.2d at 183 (Day, J., dissenting). The *Hart* court weighed the harms that the immunosuppressive drugs would cause the ill twin if she were to receive a kidney from anyone but her twin. See 289 A.2d at 389-90. The court also noted that because the twins were close, the donor-twin would benefit psychologically from participating in the kidney transplant and, therefore, the *Hart* court approved the harvest. See *id.* at 389. The *Pescinski* dissent similarly advocated a balancing of the donor and recipients' "relative need" for the organ. See 226 N.W.2d at 182-83 (Day, J., dissenting). The dissent argued that the petition should have been granted because the ill sibling would die without a kidney, whereas the mentally disabled brother would survive with only one kidney. See *id.*

¹⁹⁴ Cf. *In re Baby Boy Doe*, 623 N.E.2d 326, 330 (Ill. App. Ct. 1994) (refusing to compel a woman to undergo a cesarean section for the benefit of her nine-month old fetus). See generally *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (1978).

¹⁹⁵ See *McFall*, 10 Pa. D. & C.3d at 91-92.

¹⁹⁶ See *id.* at 91.

¹⁹⁷ See *id.* at 90.

¹⁹⁸ See *id.* at 91-92.

¹⁹⁹ *Id.* at 92 (emphasis in original).

standing its desire to condemn the defendant's refusal on moral grounds, the court concluded that under the law, a competent adult could not be forced to submit to a medical procedure for the benefit of a third party.²⁰⁰

This unequivocal protection of a competent individual's right to bodily integrity despite the needs of a third party has been echoed in the provocative context of the rights of a fetus as against the rights of its mother.²⁰¹ In 1994, the Appellate Court of Illinois held, in *In re Baby Boy Doe*, that no balancing test should be used to weigh a viable fetus's rights against the right of a competent woman to refuse a cesarean section even if honoring the woman's refusal might harm the fetus.²⁰² The oxygen supply to a thirty-five week old fetus was slowly being cut off as a result of a placental malfunction.²⁰³ The obstetrician recommended that labor be induced or a cesarean performed in order to prevent retardation or death.²⁰⁴ The mother refused, in part on religious grounds, stating that her faith in God's healing powers compelled her to await natural childbirth.²⁰⁵ The court then made three specific findings: (1) the fetus would be viable outside the womb without any medical assistance; (2) the chances that the fetus would survive natural childbirth were close to zero; and (3) the odds of the mother dying from a cesarean section were about one in 10,000.²⁰⁶

The court analogized *Baby Boy Doe* to cases protecting an individual's right to refuse medical treatment including life sustaining treatment, the right to bodily integrity and the privilege of not being compelled to undergo medical procedures for the benefit of a third

²⁰⁰ See *McFall*, 10 Pa. D. & C.3d at 91, 92.

²⁰¹ See *Baby Boy Doe*, 623 N.E.2d at 330.

²⁰² See *id.* The state argued that the fetus's own right to life should be weighed against the mother's right to consent to or decline medical treatment. See *id.* Three years later, in *In re Brown*, the Illinois Supreme Court reaffirmed and extended *Baby Boy Doe*, holding that the state's interest in preserving the life of a viable fetus was also insufficient to compel a pregnant woman to submit to medical treatment on behalf of that fetus. See 689 N.E.2d 397, 406 (Ill. App. Ct. 1997). At issue in *Brown* was a mother's refusal, on religious grounds, to accept a blood transfusion. See *id.* On appeal, the court held that the trial court had been wrong to appoint a guardian ad litem to represent the fetus and order that the blood transfusion be performed over the mother's objections. See *id.*; John J. Paris, *Planning on a Miracle: The Case of Mother Versus Fetus*, 111 CHRISTIAN CENTURY 244, available in 1994 WL 13156725 for a discussion of *Baby Boy Doe* and two additional, similar cases.

²⁰³ See *Baby Boy Doe*, 623 N.E.2d at 327.

²⁰⁴ See *id.*

²⁰⁵ See *id.*

²⁰⁶ See *id.* at 328.

party.²⁰⁷ Adopting the reasoning of other courts confronted with similar disputes, the court found that it was the "woman's decision, not the fetus's interest [that was] the only dispositive factor."²⁰⁸ Citing *Curran and Pescinski*, the court analogized the invasiveness of a cesarean section to a kidney or bone marrow harvest:

If a sibling cannot be forced to donate bone marrow to save a sibling's life, if an incompetent brother cannot be forced to donate a kidney to save the life of his dying sister, then surely a mother cannot be forced to undergo a cesarean section to benefit her viable fetus.²⁰⁹

Lastly, the court painted a graphic picture of the way in which compelled medical treatment on a competent adult would need to be carried out, highlighting how alien such a practice is in our society.²¹⁰ Therefore, the court not only determined that the woman's fundamental rights to autonomy and bodily integrity should be protected, but that the third party's interest (in this case, the fetus) should not even be factored into the analysis.²¹¹

These recent cases indicate that a competent adult's right to decline a surgical procedure for the benefit of a third party continues to be entitled to fierce protection. On the other hand, as discussed in the next section, the notion that parents and guardians have the authority to compel a minor or incompetent to undergo a surgical

²⁰⁷ See *id.* at 331 (citing *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261, 277 (1990)). See generally *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989).

²⁰⁸ See *Baby Boy Doe*, 623 N.E.2d at 332 (citing *In re A.C.*, 573 A.2d 1235, 1237 (D.C. 1990) (*en banc*)).

²⁰⁹ *Id.* at 333-34 (citations omitted). In dicta, *Baby Boy Doe* distinguished between compelling a major bodily intrusion, such as a cesarean section or an organ harvest, for the sake of the fetus, and compelling a minor bodily intrusion, such as a blood transfusion. See *id.* at 334. Three years later, the same court confronted a similar dilemma and explicitly disagreed with *Baby Boy Doe*'s characterization of a blood transfusion as a minor bodily invasion. See *Brown*, 689 N.E.2d at 405.

²¹⁰ See *Baby Boy Doe*, 623 N.E.2d at 335 (quoting *A.C.*, 573 A.2d at 1261 n.8). In *Baby Boy Doe*, the court stated: "Enforcement could be accomplished only through physical force or its equivalent. [The mother] would have to be fastened with restraints to the operating table, or perhaps . . . rendered unconscious by forcibly injecting her with an anesthetic, and then subjected to unwanted major surgery. Such actions would surely give one pause in a civilized society, especially when [the mother] had done no wrong." *Id.* Three years later, a similar tone of disapproval attended the court's comment that the mother in *Brown* had been physically restrained and sedated in order to perform the blood transfusion over her objections. See *Brown*, 689 N.E.2d at 400.

²¹¹ See *Baby Boy Doe*, 623 N.E.2d at 326.

procedure for the benefit of a third party threatens to become a legal presumption.

C. *Petitions to Harvest Organs Pave the Way for New Legal Dilemmas*

Law students learn early on about the treacherous slippery slope and its use as a rhetorical weapon to justify a court's refusal to recognize new rights and privileges. It is unusual, however, to find an opinion that starkly represents the actual slide down that slope.²¹² In 1997, in *Ferrell v. Rosenbaum*, the District of Columbia Court of Appeals recognized the right of a leukemic child to have a sibling conceived who might provide her with bone marrow.²¹³ The mother brought suit against her daughter's geneticist claiming that his failure to timely diagnose the child's leukemia constituted medical malpractice.²¹⁴ The mother claimed that by the time the diagnosis was made, she and the father were estranged, and, therefore, the geneticist's negligence robbed the mother of the opportunity to conceive additional children who might serve as bone marrow donors.²¹⁵

The court opined that it was the loss of the opportunity to survive (in the form of a potential sibling's bone marrow), rather than the loss of survival itself, that constituted the alleged harm.²¹⁶ The court's analysis of the cause in fact turned on a series of hypotheticals: *if* the diagnosis had been timely made, *and* the parents had decided to conceive another child *and* they had been successful in conceiving a child who was not only a suitable match but who did not suffer from the same genetic defect, *then* the chances the child would recover from a bone marrow transplant were in the range of seventy-five to eighty percent.²¹⁷ The court overturned the lower court's grant of summary

²¹² See generally *Ferrell v. Rosenbaum*, 691 A.2d 641 (D.C. 1997).

²¹³ See *id.* at 651.

²¹⁴ See *id.* at 643. The undisputed evidence of medical malpractice was damning: the child was born with obvious and severe physical deformities including undersized and immature thumbs and a lack of external ear canals, both symptoms of a progressive and fatal form of leukemia called Fanconi anemia. See *id.* at 643-44. On the basis of these physical abnormalities, the geneticist ordered a series of diagnostic tests, including a chromosome test. See *id.* The tests confirmed the child's condition, but in his deposition the geneticist admitted that he never reviewed the results, nor the results of additional tests taken over the next year. See *id.* at 649 n.15.

²¹⁵ See *id.* at 644, 651. The parents separated when the child was two. The mother subsequently lost touch with the father. At the time of the hearing, the father was believed to be homeless somewhere in California. See *id.* at 644.

²¹⁶ See *id.* at 651.

²¹⁷ See *Ferrell*, 691 A.2d at 650-52. The mother argued that the odds of conceiving a baby that was a genetic match but who did not share the same genetic defect were 18.75%.

judgment for the doctor/defendant, holding that a reasonable jury could find the doctor violated the standard of care, and furthermore, that the misdiagnosis was a substantial factor in the harm visited on the child because it precluded her from her best chance of obtaining a matched sibling donor.²¹⁸

The dissent argued that whether the father would have been willing to conceive other children was speculative at best, particularly given that the parents had separated when the child was only two years old.²¹⁹ The mother's assertion that he would have been willing to conceive additional children or reconcile with the mother lacked any evidentiary support.²²⁰ Without that crucial link in the chain, the dissent concluded that the mother could not prove that the geneticist's negligence was a substantial factor in the alleged harm.²²¹ The majority responded that the father would only have needed to donate sperm; therefore, whether the parents reconciled was irrelevant.²²² The court concluded that if a jury found a breach of the standard of care, "that breach was a proximate cause of [the child's] injury."²²³

Ferrell's alleged right has no precedent in case or statutory law, but does have practical and popular roots.²²⁴ Pediatric oncologists and cancer treatment centers have for many years known and approved families' decisions to conceive children as bone marrow donors.²²⁵

See id. at 652. *See also* Kearney & Caplan, *supra* note 83, at 268 (noting, curiously without comment, that the odds can be improved through "an incestuous conception between a parent and a child").

²¹⁸ *See Ferrell*, 691 A.2d at 651.

²¹⁹ *See id.* at 653 (Terry, J., dissenting).

²²⁰ *See id.* As the whereabouts of the father were unknown, this line of argument was based exclusively on the mother's assertion at her deposition.

²²¹ *See id.*

²²² *See id.* at 652. The *Ferrell* court's offhand remark equating fatherhood with sperm donor is consistent with its implicit acceptance of the practice of conceiving donor babies. Both view children and fathers in terms of their organs and bodily fluids with no thought to their value as functioning members of a family or their worth and dignity as individual human beings. *See id.* Robertson adopts a similar posture in his chapter entitled "Farming the Uterus." *See* CHILDREN OF CHOICE, *supra* note 34, at 197-219. For a thought-provoking discussion of the ethical and legal dilemmas posed by the related practice of harvesting sperm from dead and comatose men, see Lori B. Andrews, *The Sperminator*, N.Y. TIMES MAG., March 28, 1999, at 62.

²²³ *See Ferrell*, 691 A.2d at 652.

²²⁴ *See* B.D. Colen, *The Price of Life; Marrow-Donor Babies; Conception for Utility Raises Moral, Ethical Stakes*, NEWSDAY, Mar. 11, 1990, at 5 (interviewing ethicists and physicians around the country about their views on the Ayala case and the general practice of conceiving children as bone marrow donors) [hereinafter *Price of Life*].

²²⁵ *See id.* The head of the division of research immunology and bone marrow transplantation at Los Angeles Children's Hospital is quoted as saying, "I've been doing marrow

The practice came to popular attention in the early 1990s when the Ayala family publicly announced their decision to conceive a donor baby, despite their ages and the need to reverse the father's vasectomy.²²⁶ Their experience drew a great deal of attention and, while ethicists questioned the practice, the popular sentiment was overwhelmingly positive.²²⁷ Less well known, however, is the incidence of abortion for fetuses which fail to match or the incidence of adoption for babies conceived as donors.²²⁸ The *Ferrell* decision, therefore, rested on the presumption that parents not only have the authority to harvest bone marrow from a matching sibling, but can freely conceive, abort or put up for adoption children who serve as donors or who fail in their function as organ donor.²²⁹

III. ANALYSIS

Courts confronted with petitions to compel children and mentally disabled adults to undergo surgical invasions for the benefit of third parties analyze the petitions in terms of costs and benefits.²³⁰ Courts confronted with competent adults, on the other hand, have refused this approach on the grounds that it would violate the individual's right to autonomy and bodily integrity.²³¹ Differences between legally competent and incompetent individuals do not justify the dif-

transplants for 20 years . . . and I can think back to 1974 to families where I knew the child was conceived [as a marrow donor]." *Id.*

²²⁶ See *CHILDREN OF CHOICE*, *supra* note 34, at 213-14. Both parents were over forty. See *id.*; see also *Marissa Ayala*, *supra* note 34, at 78.

²²⁷ See, e.g., *Marissa Ayala*, *supra* note 34, at 79; *Price of Life*, *supra* note 224.

²²⁸ See *Price of Life*, *supra* note 224 (reporting the case of a couple who conceived a bone marrow match and then gave the child up for adoption); *Gianelli*, *supra* note 43 (reporting the case of a couple who wished to conceive, test and abort fetuses until they conceived a bone marrow match); see also *CHILDREN OF CHOICE*, *supra* note 34, at 213-14; but see *Kearney & Caplan*, *supra* note 83, at 269 (asserting that no such cases have actually been reported).

²²⁹ See *Ferrell*, 691 A.2d at 651.

²³⁰ The cost-benefit analysis has been criticized elsewhere as vague and standardless. See generally *Lebit*, *supra* note 136; *Robertson*, *supra* note 14.

²³¹ See *Greatest Gift*, *supra* note 3, at 620-21 (noting that one state statute that indeed imposes a duty to rescue "does not in any way attempt to place the value of one life over the value of another," but that a law compelling an individual to submit to a medical procedure on behalf of a third party would necessarily assume "that one individual's right to be free from 'danger of peril' is somehow less important than another's similar right"). Friedman argues that expanding the doctrine to compel Good Samaritanism "cannot legally or ethically be maintained." See *id.* at 619. But see *Huffman*, *supra* note 17, at 414-15 (suggesting a "construct" by which plaintiffs who satisfy certain criteria may obtain a court order and compel a reluctant donor to cooperate under threat of civil and criminal liability).

ferent analyses.²³² Moreover, the information on which the cost and benefit determinations have been based is incorrect, incomplete and hence, misleading.²³³

A. Costs and Benefits: The Math Is All Wrong

Courts authorizing organ harvests from legal incompetents have relied on a number of mistaken and interrelated assumptions: (1) the surgical risks of an organ harvest constitute the only risks; (2) the transplant will ensure the survival of the ill sibling; (3) the survival of the sibling will ensure the integrity and well-being of the sibling relationship and family as a whole; and (4) the donor will benefit psychologically from his or her participation in the process.²³⁴ Unfortunately, research indicates that each element of this house-of-cards justification is subject to question.²³⁵ For starters, the physical risks of surgery are not the only risks to which donors are exposed.²³⁶ In fact, the psychological harm of compelling donation may be grave, the physical benefit to the recipient may be small and the relationship between donor-recipient pairs may be permanently damaged.²³⁷

1. Information Deficits Regarding the Costs of Harvesting Organs

Because courts have ignored or been unaware of the psychological toll of being compelled to donate an organ, judicial assessments of the potential harm have been greatly underestimated. Courts applying a cost-benefit analysis to organ harvest petitions have generally measured the cost to donors in three ways: (1) the risk that death or serious injury will result from the harvest; (2) the temporary or per-

²³² See *In re Estate of Longeway*, 549 N.E.2d 292, 297 (Ill. 1989) (stating: "No right is more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of [the individual's] own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." (internal quotations omitted)).

²³³ See *infra* notes 234-75 and accompanying text.

²³⁴ See generally *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990); *In re Doe*, 481 N.Y.S.2d 932 (N.Y. App. Div. 1984) (per curiam). But cf. *Lawse v. Univ. of Iowa Hosps.*, 434 N.W.2d 895 (Iowa Ct. App. 1988) (noting that family members may rarely be able to give an informed consent to donate an organ because of pressure from family and medical personnel).

²³⁵ See *supra* notes 69-77, 89-94 and accompanying text (health prospects for transplant recipients); *supra* notes 85-88, 120 and accompanying text (estrangement of donor-recipient post-transplant); *supra* note 43 and accompanying text (harvesting procedures).

²³⁶ See *supra* notes 46-94 and accompanying text.

²³⁷ See *Kallich & Merz*, *supra* note 11, at 145 (noting that "considerable disagreement exists in the field of transplantation regarding the risks of donation . . ."); *supra* notes 85-88, 120 and accompanying text.

manent physical changes that the harvest will cause; and (3) the overall level of surgical complication or invasiveness of the procedure.²³⁸ By measuring the costs to the incompetent in physical terms, courts have implied that absent a physical harm, there can be no psychological harm.²³⁹ Research has shown this to be an incorrect implication.²⁴⁰

As noted in Part I, to date, only one study has focused on the effects of organ harvests on minor sibling-donors—that is, on the psychological effects of being volunteered by one's parents to donate bone marrow to an ill sibling.²⁴¹ That study revealed that the young donors were withdrawn, anxious, depressed, had lowered self-esteem and exhibited symptoms of post-traumatic stress disorder.²⁴² Although the body of research into the psychological effects of organ harvests on adult sibling-donors is far from robust, it supplements the little evidence we have regarding incompetent donors. The latter studies reveal that even the most favorable circumstances attending an adult donor's participation do not necessarily insulate him or her from psychological harm.²⁴³ Donors are often plagued by the worry that the donor's bone marrow will immunologically attack the recipient's body or that the kidney will be rejected.²⁴⁴ Rather than mark the turning point for patients and families after a prolonged and debilitating illness, the transplant can mark the beginning of a grueling treatment process that leads to a death more agonizing than death from the underlying disease.²⁴⁵ The donor's guilt from having caused or contributed to that suffering can be great.²⁴⁶ These harms occur among adult sibling donors even when the decision to donate is voluntary, even when there is an established relationship between the donor and recipient and even when the ill family member becomes a long-term,

²³⁸ See *Hart v. Brown*, 289 A.2d 386, 389 (Conn. Super. Ct. 1972) (noting that kidney donor would only be restricted from contact sports and the surgery would only last two and one-half hours); *Doe*, 481 N.Y.S.2d at 933 (noting that bone marrow harvest posed minimal medical risk). But see *Curran*, 566 N.E.2d at 1344–45. Although *Curran* turned on the psychological effects on the young donors, the psychological harm that so concerned the court was limited to the mother's inability to provide the twins the necessary emotional support; the court was either unaware of or unconcerned about the potential psychological harm flowing from participation in the bone marrow harvest itself. See *id.*

²³⁹ See *Hart*, 289 A.2d at 389; *Doe*, 481 N.Y.S.2d at 933.

²⁴⁰ See *supra* notes 38–90 and accompanying text.

²⁴¹ See *supra* notes 73–77 and accompanying text.

²⁴² See Kaarela, *supra* note 33.

²⁴³ See *supra* notes 79–83 and accompanying text.

²⁴⁴ See *supra* notes 58–69 and accompanying text.

²⁴⁵ See *supra* notes 58–69 and accompanying text.

²⁴⁶ See *supra* notes 58–69 and accompanying text.

disease-free survivor.²⁴⁷ Favorable circumstances, however, are often absent; pressure to donate can be coercive and family dynamics and agendas often subtly—or overtly—guide selection of the donor.²⁴⁸ As a consequence, the potential for psychological harm rises.²⁴⁹

Perhaps more importantly, evidence that adult related donors suffer psychological harm should sound an alarm for those concerned about the welfare of children and mental incompetents precisely because of key differences between the two sets of people: adults have real world options and internal resources that are simply unavailable to the legal incompetent.²⁵⁰ Being an adult means making choices that are guided by and, in turn, contribute to the development of one's internal moral compass.²⁵¹ Furthermore, being an adult means that even if one feels compelled to act, ultimately one chooses to give in to the compulsion.²⁵² Unlike children and mentally disabled adults, adult prospective donors have the maturity and legal standing to decline to be tested for compatibility or to bring the organ procurement process to a halt at any time.²⁵³ Ambivalent and fearful, yet psychiatrically stable, adults may even be provided with mock medical reasons to relieve them of further family pressure and excuse them from any familial obligation.²⁵⁴

To the extent that courts adjudicating organ harvest petitions recognize the potential for psychological harm, they answer it by inviting experts to testify.²⁵⁵ Courts hope this testimony will reveal any unseemly intention guiding the parent or guardian's selection of the

²⁴⁷ See *supra* notes 80–82 and accompanying text.

²⁴⁸ See *supra* notes 103–13 and accompanying text.

²⁴⁹ See *BMT Donors*, *supra* note 33, at 487 (noting researchers' concerns that because estranged donors and recipients refused to participate in the study, the difficulties reported by the study participants were only the "tip of the iceberg").

²⁵⁰ See *supra* notes 54–90 and accompanying text.

²⁵¹ See *supra* notes 95–103 and accompanying text.

²⁵² See *supra* notes 95–103 and accompanying text.

²⁵³ See, e.g., *McFall v. Shimp*, 10 Pa. D. & C.3d 90, 91–92 (1978) (refusing to compel a competent adult to undergo a bone marrow harvest for the benefit of his cousin); *In re Pescinski*, 226 N.W.2d 180, 183 (Wisc. 1975) (Day, J., dissenting) (noting the "impracticality" of obtaining an organ from another brother when, in fact, the brother had simply exercised his right to refuse to donate); cf. Friedman Ross, *supra* note 16. During the experimental phase of a living donor liver-transplantation program, parents of small children with liver disease underwent a psychiatric evaluation. When asked about their willingness to donate a portion of their livers the parents "were able to say no even when the lives of their children were at risk and no alternative therapies (such as dialysis) were available." See *id.*

²⁵⁴ See *supra* notes 117–18 and accompanying text.

²⁵⁵ See, e.g., *Hart*, 289 A.2d at 389–90.

particular donor or that it will indicate whether the selected donor runs a particular risk of sustaining psychological harm.²⁵⁶ This evaluation process, however, offers little protection to the average child or mentally disabled adult for two reasons. First, it suggests that only the rare individual, either because of extraordinary circumstances or a predisposition to psychiatric problems, will suffer psychological harm.²⁵⁷ Second, it assumes that a certain level of fear and uncertainty is acceptable—an assumption courts will not make about competent adults.²⁵⁸ Moreover, in the rare circumstance that a child or mentally disabled adult does attempt to say “no” to the harvest, medical personnel and family members treat the incompetent as merely afraid, not unwilling.²⁵⁹ The ambivalent and fearful, yet psychiatrically stable, child or mentally retarded adult will not receive the graceful exit from the process that the competent adult is entitled to. Rather, he or she can expect a sympathetic hand to hold while being put under anesthesia and, perhaps, counseling post-harvest to help integrate the experience of having been compelled to undergo the surgery.²⁶⁰ However, neither the process by which children and mentally disabled adults become donors, nor a post-facto therapeutic Band-Aid can

²⁵⁶ See *id.* at 374; *Little v. Little*, 576 S.W.2d 493, 499 (Tex. App. 1979, writ denied).

²⁵⁷ See *Curran*, 566 N.E.2d at 1338, 1343 (predisposition to psychological harm measured in terms of the mother's inability, because of her objections to the bone marrow harvest, to provide emotional support during the frightening, unfamiliar hospital procedure). But see *Little*, 576 S.W.2d at 499. The *Little* court noted that the donor who had Down's Syndrome had a “high threshold for pain” but that her limited intelligence might make the experience “more burdensome” than it would be for an adult. These factors, however, did not, apparently, amount to any peculiar disposition for psychological harm nor unusual circumstance warranting the court's concern. See *id.* at 499.

²⁵⁸ See *Curran*, 566 N.E.2d at 1338.

The very young donor is going to be afraid to come into the hospital, just like any three and a half year old would be. We show them the place that they'll be staying. In many cases we'll take them up to the operating room and show them that. We can use play therapy with a doll or with a teddy bear. . . . We have facilities for the parent to stay with the child both before and after the procedure.

Id.; see also *Little*, 576 S.W.2d at 499.

²⁵⁹ See *Curran*, 566 N.E.2d at 1338, 1343; see also *Baron*, *supra* note 8, at 191.

²⁶⁰ See *Curran*, 566 N.E.2d at 1338, 1343 (noting that the consent and emotional support of the parent “is important to ease the fears associated with such an unfamiliar procedure”); see also *Baron*, *supra* note 8, at 191 (reporting a Maryland court that left open the question of whether the medical providers would be “required to offer the donor follow-up psychiatric care.”).

remedy the fundamental wrong of placing these individuals in the role of family rescuer.²⁶¹

That this complex array of psychological harms has gone largely unnoticed by courts confronted with petitions to harvest organs from legal incompetents is made all the more troubling by the fact that the *benefits* imputed to the incompetents are entirely psychological.²⁶² Psychological benefits cannot accurately be measured if psychological harms have been omitted from the equation. And, as discussed below, one must question whether courts are correct to impute the psychological benefits of an altruistic adult donor to the incompetent who is compelled to donate an organ.²⁶³

2. Information Deficits Regarding the Benefits of Harvesting Organs

As noted above, courts underestimate the costs associated with donating organs by omitting the psychological costs. At the same time, courts inflate the benefits side of the equation by adding theoretical psychological benefits.²⁶⁴ That courts are willing to entertain speculation about psychological benefits is understandable: organ transplants provide no medical benefit to the donor, therefore any benefit would have to be psychological.²⁶⁵ Nevertheless, research does not support the optimism that attends the speculations.²⁶⁶

In every reported case in which an organ transplant has been permitted, courts have relied on the assumption that the compelled donor would realize one of two psychological benefits: the opportunity to maintain a relationship with the recipient-sibling and the psychological benefit of having acted altruistically.²⁶⁷ Taking these

²⁶¹ See *Curran*, 566 N.E.2d at 1338, 1343. But see *Little*, 576 S.W.2d at 499.

²⁶² See *Hart*, 289 A.2d at 387 (noting that transplant will lead to the family being "happy" rather than "distressed"); *Doe*, 481 N.Y.S.2d at 933 (noting that donor will benefit from advocacy and company of recipient); cf. *Curran*, 566 N.E.2d at 1344-45 (noting that donors lacked sufficient relationship with sibling-patient to expect them to benefit psychologically). Baron notes that it is the rare guardian ad litem who fights the petition to authorize an organ harvest. See Baron, *supra* note 8, at 184-85. More commonly, all parties come to the court having already agreed that the recipient's benefits outweigh the donor's harms. See *id.* This may explain the lack of judicial ink on the subject.

²⁶³ See *infra* notes 269-86 and accompanying text.

²⁶⁴ See *Doe*, 481 N.Y.S.2d at 933; *Little*, 576 S.W.2d at 499; *infra* notes 269-86 and accompanying text.

²⁶⁵ See *supra* notes 81-84, 114 and accompanying text.

²⁶⁶ See *supra* notes 59-80 and accompanying text.

²⁶⁷ See *Hart*, 289 A.2d at 387; *Doe*, 481 N.Y.S.2d at 933; cf. *Curran*, 566 N.E.2d at 1344 (denying petition to compel a bone marrow harvest where there was no established relationship between the half-siblings).

benefits in turn, the expectation that the sibling relationship will be unaffected or improved by the transplant may go unmet.²⁶⁸ The link between donors and recipients is such that the donor's psychological well-being and a continued relationship with the recipient may depend on the recipient's perception of his or her ongoing well-being and the long-term success of the transplant.²⁶⁹ Aggressive cancer treatments, however, often offer no more than a minimal chance of survival, yet carry a significant risk that the treatment will harm the patient or lead to a painful and protracted death.²⁷⁰ In addition, the treatment can exact a huge financial and emotional toll on the family.²⁷¹ Therefore, because transplants rarely yield a return to perfect health, the link between donors and recipients created by the transplant can lead to a deterioration in the quality and strength of the ongoing relationship.²⁷² Moreover, the benefits of an enhanced or ongoing relationship may not manifest even if the transplant is a medical success.²⁷³ If the donor was at all ambivalent about donating, the recipient may forever hold it against him despite the fact that he ultimately came through.²⁷⁴ The recipient's feelings of debt or guilt from having needed so great a sacrifice from the donor can also create an unbridgeable gap between the two family members.²⁷⁵

Alternatively, courts impute to volunteered children and mentally disabled adults the psychological benefits that may flow to competent adult volunteers.²⁷⁶ Courts and commentators use words like "donation," "gift" and "altruism" to support this assignment of benefits.²⁷⁷ Neither the language nor the imputed benefits reflect the experience

²⁶⁸ See *supra* notes 81–84, 111–14 and accompanying text.

²⁶⁹ See *supra* notes 62–63 and accompanying text.

²⁷⁰ See generally *Newmark v. Williams*, 588 A.2d 1108, 1118 (Del. 1990). The *Newmark* court upheld the parent's right to refuse an aggressive course of cancer treatment which doctors believed was the only hope for their three-year-old leukemic child. See *id.* at 1110. Doctors considered the treatment "the most aggressive form of cancer therapy short of a bone marrow transplant." See *id.* at 1118. If the treatment itself did not kill the boy, it would offer him a forty-percent chance of survival, measured not in terms of cure, but in terms of living for two additional years, cancer free. See *id.* at 1118, 1119 n.12.

²⁷¹ See *id.*

²⁷² See *supra* notes 58–63 and accompanying text.

²⁷³ See *supra* notes 81–84, 111–14 and accompanying text.

²⁷⁴ See *supra* note 82.

²⁷⁵ See *GIFT OF LIFE*, *supra* note 16, at 171–72; *supra* note 90 and accompanying text.

²⁷⁶ See *Curran*, 566 N.E.2d at 1325, 1344–45; Baron, *supra* note 8, at 178.

²⁷⁷ See *Curran*, 566 N.E.2d at 1325, 1344–45; Baron, *supra* note 8, at 178; Robbenmolt, *supra* note 10, at 228 (arguing that the best interests standard is flawed precisely because it "imposes self-seeking values upon children" and "fails to allow [them] to act altruistically.").

of the legally incompetent individual compelled to undergo a surgical invasion for the benefit of a third party.²⁷⁸ Commentators argue that retaining the language of voluntariness reminds us that parents have beneficent motives when they involve their children in the organ procurement process.²⁷⁹ Compassion for parents, however, is an insufficient justification for employing euphemisms.²⁸⁰ While the term "organ donor" is an efficient catchall phrase for the process by which human organs are obtained for transplantation, in this context, verbal efficiency masks meaningful differences between the affirmative act of giving and the passive experience of having something taken away.²⁸¹

Concerns about coercive family pressure, physical and psychological harm, the proper respect for individual autonomy and inappropriately imputed psychological benefits are intensified for the child conceived as an organ donor.²⁸² Those who approve of, or who are at least unwilling to criticize these practices argue that questionable, selfish motives often underlie people's decisions to have a child or terminate a pregnancy.²⁸³ If we are not going to police every decision, so the argument goes, then we cannot police any decision.²⁸⁴ But this view glosses over a material difference between conceiving children who may, as individuals, serve their parents' ends and conceiving

²⁷⁸ Cf. *Curran*, 566 N.E.2d at 1334 (psychiatrist testified that young "mentally and physically healthy children do not understand abstract concepts such as death because they just haven't had the opportunity to have cognitive development sufficient to manage things like abstractions, hypotheses, and so on.") (internal quotes omitted).

²⁷⁹ See Kearney & Caplan, *supra* note 83, at 264.

²⁸⁰ See Dobson, *supra* note 81 ("Adults are not usually compelled to display altruism, but children are regularly 'volunteered' by their parents.").

²⁸¹ See *id.*; *supra* notes 78-84, 98-125 and accompanying text.

²⁸² See Kearney & Caplan, *supra* note 83, at 274. "In the immediacy of the desire to save the life of a family member, there may be an undue emphasis on the conceived child's purpose in saving another life. This could arise from the parents themselves, their families, or others in their community. . . ." *Id.*

²⁸³ Professor George Annas of Boston University Law School was quoted as saying: "[W]e're going to have to depend upon the good sense of the medical community to discourage this, and so far the medical community hasn't shown much sense. I hope we don't get to . . . where we have to legislate this, but we will if it becomes a big thing." *Price of Life*, *supra* note 224; see Kearney & Caplan, *supra* note 83, at 282. But see *CHILDREN OF CHOICE*, *supra* note 34, at 211-17. Robertson argues that the only difference between conceiving with the intention to "farm the uterus" for tissue and then aborting versus conceiving and then deciding to abort for any other personal reason is purely symbolic. See *id.* at 213-14. "Deliberate creation of fetuses to be aborted for tissue procurement is more ethically complex and defensible than its current widespread dismissal would suggest." *Id.* at 214.

²⁸⁴ See *CHILDREN OF CHOICE*, *supra* note 34, at 215; *Price of Life*, *supra* note 224 (quoting the director of the Center for Biomedical Ethics at Case Western Reserve Medical School in Cleveland that few decisions to have children can "stand up to rational scrutiny.").

children whose *body parts* may serve their parents' ends.²⁸⁵ In the former case, the children will inevitably grow into adults and, as adults, will have the autonomy to choose to fulfill or disappoint their parents' expectations.²⁸⁶ Children conceived as organ donors, on the other hand, are never given the opportunity to break from their parents' expectations by making their own choices.²⁸⁷ Parity for donation—the act of conceiving a child to produce an organ donor—reflects a dissected view of children that is incompatible with current understandings of the psychological development of identity and the social and legal concepts of individual autonomy.²⁸⁸ Prohibiting harvests from minors and mentally disabled adults is the only way to eliminate the incentive to conceive children to create matching donors.²⁸⁹

When it overturned the lower court's decision granting summary judgment to the geneticist, *Ferrell v. Rosenbaum* recognized the legal viability of the mother's novel claim that medical negligence robbed her of the opportunity to conceive potential bone marrow donor-siblings for her daughter.²⁹⁰ In recognizing the claim, *Ferrell* took one giant step toward recognizing one individual's right to claim the organ of another.²⁹¹ What happens then to the family who refuses to conceive another baby, or the family that refuses to volunteer its other children to be tested for compatibility?²⁹² Might a court find that a parents' duty to care for an ill child extends to compelling the parents

²⁸⁵ See *Price of Life*, *supra* note 224 (quoting a senior associate from one of the nation's leading bioethics think tanks, "[i]t's the classic nightmare of using people as tissue and organ banks, and . . . we have to respond to it as the classic nightmare. There's a revulsion that . . . kick[s] in.").

²⁸⁶ See generally CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT, 151–74 (2d ed. 1993).

²⁸⁷ See *Price of Life*, *supra* note 224 (stating: "What is the purpose of any human being or child? . . . [I]t's not to be used as an object for another person").

²⁸⁸ See *id.*

²⁸⁹ See *id.*

²⁹⁰ See 691 A.2d 641, 651 (D.C. 1997) (vacating the superior court's grant of summary judgment on the grounds that the geneticist's negligence was a substantial factor in the child's injury).

²⁹¹ See *id.*

²⁹² See Kearney & Caplan, *supra* note 83, at 279 (expressing the concern that to the extent the state's interest in a woman's reproductive process is unsettled, the possibility exists that a woman could be legally compelled to conceive and carry a donor baby to term).

A 1990 news article reported that a couple consented to use their six year-old daughter as a bone marrow donor for their leukemic son only after a court threatened to charge them with child abuse and remove the children from the home. See Andrea Boroff Eagan, *Who Decides for Women?*, AMERICAN HEALTH, Sept. 1990, at 42. Eagan contrasts this with the report of an Arkansas man who refused to donate bone marrow to his leukemic brother but was left in peace. See *id.*

to conceive other children as organ donors?²⁹³ Ferrell, the Ayala story and similar news reports transform these extreme hypotheticals into realistic possibilities.²⁹⁴

Adults experience psychic or psychological benefits when they act without any expectation of reward and when they do not bear the burden of the life or death of a loved one.²⁹⁵ Altruistic behavior is made possible by advances through stages of cognitive development.²⁹⁶ Children do not achieve the ability to act altruistically until sometime in early adolescence, and mentally disabled adults may never reach that stage.²⁹⁷ Imputing the psychological benefits of altruistic behavior to individuals who, because of age, cognitive ability and circumstances cannot make altruistic choices, is myopic.²⁹⁸ Whatever lesson the child may learn from being compelled to donate an organ or from being conceived to donate an organ, it surely will not be about the good of giving of oneself utterly and selflessly.²⁹⁹

²⁹³ See Eagan, *supra* note 292; cf. *Bone Marrow Dispute*, WASH. POST, Jan. 20, 1990, at B5. A Virginia woman filed a claim against the father of her four month-old son to compel him to be tested for bone marrow compatibility as it was his "duty and obligation to undergo minimally intrusive tests and, if eligible, to donate bone marrow to his son." See Eagan, *supra* note 292; cf. *Bone Marrow Dispute*, *supra*, at B5 (internal quotes omitted). USA Today followed the story and interviewed ethicists who logged their disapproval of compelling a parent to donate to their child. See Andrea Stone, *Father Sued for Bone Marrow*, USA TODAY, Jan. 19, 1990, at 3A. The news reports noted that the woman had repeatedly pleaded with the father to come forward and he had refused. A week after the story broke, however, the claim was dropped when the father underwent tests, claiming that he had been unaware that a sample of his blood had been sought. See *id.*

²⁹⁴ See Kearney & Caplan, *supra* note 83, at 279; Eagan, *supra* note 292.

²⁹⁵ Cf. Curran, 566 N.E.2d at 1335 (reporting psychiatrist's testimony that whether a child feels guilty about not having donated will depend entirely on the parent taking responsibility for having made a difficult decision and not laying the burden on the child); see GIFT OF LIFE, *supra* note 16, at 444-45.

²⁹⁶ See Curran, 566 N.E.2d at 1334; see also *supra* notes 102-10 and accompanying text.

²⁹⁷ See Nathan Seppa, *Teens' Altruism Grows Like They Do-In Sports*, APA MONITOR, June 1996; cf. Curran, 566 N.E.2d at 1334 (noting a psychiatrist's testimony that "mentally and physically healthy children do not understand abstract concepts such as death because they just haven't had the opportunity to have cognitive development sufficient to manage things like abstractions, hypotheses, and so on.").

²⁹⁸ See Curran, 566 N.E.2d at 1334; Seppa, *supra* note 297; *supra* notes 103-125 and accompanying text.

²⁹⁹ See Curran, 566 N.E.2d at 1334; Seppa, *supra* note 297; *supra* notes 103-125 and accompanying text.

B. No Judicial Standard or Adjudicative Proceeding Will Uniformly Lead to the Proper Result

Adjudicating petitions to harvest organs on a case-by-case basis tempts judges to stretch legal doctrine to the breaking point in order to reach what they hope is the least regrettable decision.³⁰⁰ The heartwrenching issues these petitions involve make this inevitable.³⁰¹ Commentators have suggested various methods of correcting the inherent dangers of the current system, including adopting stricter, more clearly defined standards, changing the forum in which the petitions are heard and assigning experienced guardians ad litem to all donors.³⁰² None of these proposals, however, goes to the heart of the problem; case-by-case adjudications are inherently flawed because they substitute the consent and judgment of a third-party decision-maker for the consent and judgment of the individual undergoing the surgical invasion.³⁰³ It is immaterial whether that third-party decisionmaker is a judge or a board of impartial experts, whether the decision is made by a state court or an administrative board, or whether more advocates are added to the complicated mix of people already involved in these petition.³⁰⁴ The harm is done when substitute deci-

³⁰⁰ See *Hart*, 289 A.2d at 390. The *Hart* court expressed the dilemma: "[The] question before this court is whether it should abandon the [recipient] to a brief medically complicated life and eventual death or permit the . . . parents to take some action based on reason and medical probability in order to keep both children alive." *Id.*; see also *Baron*, *supra* note 8, at 183.

³⁰¹ See *Hart*, 289 A.2d at 390; *Baron*, *supra* note 8, at 183.

³⁰² See, e.g., *Baron*, *supra* note 8, at 187 (suggesting that guardians ad litem be appointed for all donors, that all guardians be members of an established panel to ensure that the attorneys in that role have some expertise in the area and further, that proceedings take place in probate court because probate judges deal daily with "intrafamily conflict and tension"); Linda Delaney et al., *Altruism by Proxy: Volunteering Children for Bone Marrow Donation; Opinions of Various Professionals*, 312 *BRITISH MED. J.* 240 (1996) (suggesting that "a forum, independent of the parents and medical advisers" made up, perhaps, of independent medical social workers should be responsible for deciding the petitions); Griner, *supra* note 101, at 608-10 (advocating adoption of a rebuttable presumption against harvesting organs from minors which could only be overcome by clear and convincing evidence that the donor would benefit physically or financially); Lebit, *supra* note 136, at 127-29 (suggesting a "higher scrutiny best interests standard" which would require clear and convincing evidence that a compelled procedure is in the child or mentally disabled adult's best interests, the evidence to be provided in large part by the legal, medical and philosophical communities).

³⁰³ See *Baron*, *supra* note 8, at 187; *Delaney*, *supra* note 302; *Griner*, *supra* note 101, at 608-10; *Lebit*, *supra* note 136, at 127-29.

³⁰⁴ See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 428 (Mass. 1977). In *Saikewicz*, the court stated:

sionmakers make the kind of intensely personal and medically unnecessary decision on behalf of an incompetent that few would suggest ought to be made on behalf of a competent individual.³⁰⁵

Criticizing those decisions that reached the wrong result does not get us very far, however. Rather, *Curran*, the decision that reached the right result after applying a closely tailored best interest analysis, best illuminates the dangers inherent in adjudicating these petitions case-by-case.³⁰⁶ The *Curran* court denied the father's petition to harvest bone marrow from his three year-old twins for the benefit of their half-brother.³⁰⁷ The court articulated a three factor test to determine whether the organ harvest was in the best interests of the minor twins.³⁰⁸ *Curran's* test focused on the need for the parents' informed consent to the procedure, their willingness to emotionally support the donor and the closeness of the relationship between the donor and the ill sibling.³⁰⁹

Applying its tailored analysis to the facts before it, the *Curran* court determined that the harvest was not in the twins' best interests because the relationship between the twins and their terminally ill half brother was not close, and the custodial parent was unwilling to consent to the harvest and therefore, unable to emotionally support the twins.³¹⁰ The guidelines the *Curran* court injected into the for-

The significant decisions of life are more complex than statistical determinations. Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the unique perspective of the person called on to make the decision. To presume that the incompetent person must always be subjected to what many rational and intelligent persons may decline is to downgrade the status of the incompetent person by placing a lesser value on his intrinsic human worth and vitality.

Id.; see also Baron, *supra* note 8, at 187; Delaney, *supra* note 302; Griner, *supra* note 101, at 608-10; Lebit, *supra* note 136, at 127-29.

³⁰⁵ See Dolgin, *supra* note 13, at 399, 413-14. Dolgin further argues that substitute—or paternalistic decisions—may inflict harm rather than protect children from harm. See *id.* at 413. As an example, Dolgin discusses court decisions which require young, pregnant teenagers to petition judges for permission to undergo abortions. See *id.* While adult women may seek abortions without having to justify, or even understand, the basis of their decision, such procedures demand that the teenager be able to articulate the reasons underlying her decision to seek an abortion in the intimidating setting of a judge's chamber or courtroom. See *id.* at 414. Dolgin's argument is that this procedural requirement burdens, rather than protects, a teenager's right to terminate a pregnancy. See *id.*

³⁰⁶ See generally *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990).

³⁰⁷ See *id.* at 1344.

³⁰⁸ See *id.* at 1325-26, 1343-44.

³⁰⁹ See *id.*

³¹⁰ See *id.* at 1343-44.

merly ad hoc standard, however, do not provide legal incompetents with any greater protection than they received from courts applying any other standard. This is so because: (1) *Curran's* best interest standard relies on the same false assumption, rampant throughout these opinions, that psychological benefits will flow to siblings who have an established relationship and that the relationship will immunize the donors from psychological harm;³¹¹ and (2) the "new" standard very much defers to parental authority—in this case, the refusal of one parent to consent on behalf of the children.³¹² Looked at through this lens, *Curran* hardly lives up to the ground-breaking, controversial reputation it seems to have developed among commentators.³¹³

Both the straightforward cost-benefit analysis and *Curran's* more tailored benefits-only analysis distort the original purpose of the best interest standard.³¹⁴ Rather than safeguard children from cold, marketplace realities, the analysis permits courts to put the legally incompetent individual's right to autonomy and bodily integrity on a scale.³¹⁵ Whereas judicial proceedings offer legal incompetents only minimal protection against being compelled to "act" altruistically, the law and the medical community categorically protect competent adults from that same compulsion.³¹⁶ Differences between the two groups do not justify such disparity of treatment.³¹⁷ Ultimately, no judicial standard will lead consistently to the proper result because no standard can account for the fact that children and mentally incom-

³¹¹ See *Curran*, 566 N.E.2d at 1335; *supra* notes 81–84, 114 and accompanying text.

³¹² See *Curran* 566 N.E. 2d at 1343; see also *Wisconsin v. Yoder*, 406 U.S. 205, 234 (1972); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923).

³¹³ See, e.g., Dufault, *supra* note 37, at 230; Robbenmolt, *supra* note 10, at 216–17.

³¹⁴ See Dolgin, *supra* note 13, at 361.

³¹⁵ See *Curran*, 566 N.E. 2d at 1339–40; cf. Patricia Huna, *Infants as Organ Transplant Donors: Should it Happen?*, 6 SUM. HEALTH LAW. 24, 26 (1992). Huna adheres to the belief that the best interest standard removes third-party interests from the equation and goes on to argue that that is one of the failings of the test. See Huna, *supra*, at 26. Only those courts committed to denying the parents' request, however, actually apply the test in this way. See generally *In re Richardson*, 284 So. 2d 185, 186 (La. Ct. App. 1973); *In re Pescinski*, 226 N.W.2d 180 (Wisc. 1975). Courts determined to permit the harvest routinely weigh the costs to the recipient against the benefit to the donor, and thereby, reinsert third-party interests back into the equation. See generally *In re Doe* 481 N.Y.S.2d 932, 933 (N.Y. App. Div. 1984); *Little v. Little*, 576 S.W.2d 493, 497 (Tex. Civ. App. 1979).

³¹⁶ See, e.g., *In re Baby Boy Doe*, 623 N.E.2d 326, 330 (Ill. App. Ct. 1994); *McFall v. Shimp*, 10 Pa. D. & C.3d 90, 90 (1978). For two arguments that adults should be compelled to be tested or donate organs, see generally *Anderson*, *supra* note 98, and *Huffman*, *supra* note 17.

³¹⁷ See *Griner*, *supra* note 101, at 608.

petent adults are not only unable to give a meaningful, fully informed, legally valid "yes," they are also unable to simply say "no."³¹⁸

C. Organ Harvests from Children and Mentally Disabled Adults Should Be Prohibited

The presumption that parents and children are not adversaries with disparate interests is deeply rooted in this country's jurisprudence and legislation, and for good reason.³¹⁹ The state has an interest in preserving and protecting family autonomy because the family unit is able to fulfill social functions that the state may be unable or less able to fulfill.³²⁰ Although parents have a fundamental right to control the environment in which a child grows, that right should not extend to invading one child's body in the hope that another child might benefit.³²¹ Deference to a parent's desire and authority merely assumes away the problem of how to adequately protect the disparate interests of all family members when those interests collide.³²²

The roles that family members play within their small social units have undergone significant shifts in the past thirty years.³²³ No longer must people silently lose their individuality and autonomy as a neces-

³¹⁸ See Dobson, *supra* note 81; *supra* notes 116-17 and accompanying text.

³¹⁹ "The state cannot presume that a child and his parents are adversaries." Griffith, *supra* note 4, at 315 (quoting Santosky v. Kramer, 455 U.S. 745, 760 (1982) (termination of parental rights)); but see Baron, *supra* note 8, at 186 (arguing that despite the "natural distaste" for subjecting family members to an adversarial, judicial proceeding, "here, as in intrafamily and juvenile delinquency proceedings, the imposition of some emotional burdens on family members is necessary because the interests protected by the process are substantial and the costs of using a nonadversarial system are quite high.").

³²⁰ See Dolgin, *supra* note 13, at 363. The family unit is the optimal social structure for "preparing children to become productive members of society, developing religious and cultural diversity among citizens, and fulfilling support obligations that would otherwise fall to the state." See Griffith, *supra* note 4, at 289.

³²¹ See Wisconsin v. Yoder, 406 U.S. 205, 232 (1972) (stating that the "primary role of the parents in the upbringing of their children is now established beyond debate as an enduring American tradition."). However, while "[p]arents may be free to become martyrs themselves . . . it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves." See Prince v. Massachusetts, 321 U.S. 158, 170 (1944). For an examination of more recent Supreme Court opinions touching on the constitutional rights of children to make choices for themselves that differ from those of their parents, see generally Dolgin, *supra* note 13.

³²² See generally DeShaney v. Winnebago Co. Dept. of Social Serv., 489 U.S. 189 (1989) (denying claim that the state has a constitutional duty to protect a child from parental abuse notwithstanding the state's awareness of the abuse and the child's resulting permanent disability).

³²³ See Dolgin, *supra* note 13, at 364.

sary consequence of their family membership.³²⁴ Understandings about child development and the abilities of the mentally disabled have undergone a similar change.³²⁵ No longer are children viewed as simply miniature-sized adults, nor the mentally disabled viewed as defective human beings.³²⁶ Emerging technologies, shifting social demographics, and developments in the social and brain sciences are just some of the factors that have contributed to this evolution of family and society.³²⁷ As a society evolves, so must its body of law.

Sometimes, it is the common law that can best reflect and respond to baseline shifts in the social order; at other times legislative action is necessary to adequately articulate newly defined rights and duties and to provide guidance for how to protect and enforce these new rights and duties.³²⁸ Previously, children who were otherwise qualified could hold the same jobs as adults, and children as young as twelve could legally marry.³²⁹ Today, the age of consent in most states has risen from twelve to eighteen; child labor laws have been passed to keep children out of factories; and although children over fourteen may work, their employment is subject to strict statutory guidelines.³³⁰ These laws have restricted children's participation in adult activities, notwithstanding the family's social or economic needs which child labor or an early marriage might have satisfied.³³¹

The only solution to this dilemma is legislation which requires that an individual be legally competent to give an informed, valid

³²⁴ See *id.* at 357 (discussing *Griswold* and noting that the body of family case law was almost exclusively developed during the 1960s and 1970s).

³²⁵ See Deborah Hardin Ross, *Sterilization of the Developmentally Disabled: Shedding Some Myth-Conceptions*, 9 FLA. ST. U. L. REV. 599, 600 n.5 (1981) (noting that historically, the mentally retarded individual has been considered a "menace," a "subhuman organism," "diseased," an object of "pity," "dread" or "ridicule," or an "eternal child"). Today, medication and appropriately tailored educational opportunities permit many mentally disabled adults to be high functioning and semi-independent. See, e.g., The Arc of the United States (The National Organization of and for People With Mental Retardation and Related Disabilities and Their Families), (visited February 1, 2000) <<http://www.thearc.org/>>.

³²⁶ See Dolgin, *supra* note 13, at 361.

³²⁷ See generally Dolgin, *supra* note 13.

³²⁸ See *id.* at 370-71. The case law is "contradictory and uncertain" in its response to the changing status of children and childhood. "[S]ometimes children . . . are assumed to be best protected when their individuality is . . . subsumed by parental authority. . . . [S]ometimes children are recognized as complete human beings. . . . Sometimes the law reinforces parental authority even against children burdened by the exercise of that authority." See *id.*

³²⁹ See *id.* at 361 n.84.

³³⁰ See 29 C.F.R. § 570.2 (1998) (child labor regulations); Dolgin, *supra* note 13, at 406.

³³¹ See 29 C.F.R. § 570.2 (1998) (child labor regulations); Dolgin, *supra* note 13, at 406.

consent before he or she may be a candidate for organ donation.³³² Legislation which prohibits children and mentally disabled adults from being volunteered as donors would also eliminate the incentive parents currently have for conceiving children as donors.³³³ Furthermore, legislation would effectively halt the slide down the slippery slope threatened by the court's recognition of the malpractice claim in *Ferrell*.³³⁴ Our legal system should no longer condone compelled organ harvests by resorting to idealized notions of the family and unrealizable expectations of altruistic behavior.³³⁵

CONCLUSION

Children and mentally disabled adults are often volunteered to undergo surgical procedures so that third parties might benefit from their organs, while the legal system staunchly protects the competent adult's right to opt out of the same procedures.³³⁶ These inequitable results are not justified. The notion that parents, guardians and judges adequately protect the child and mentally disabled adult's best interests when they permit the harvests is not supported by research regarding the adverse psychological effects that flow from organ transplants.³³⁷ If the psychological benefits courts and commentators cite are at best speculative when an individual chooses to undergo a surgical invasion, they are impossible to predict when the surgical invasion is compelled. Legislation must be drafted that eliminates volunteered donors from the rolls of donor candidates, because, as long as children and mentally disabled family members are legal organ sources, parents, doctors and judges will be faced with the untenable task of harming one child in the hope that another will be saved.

We live in a remarkable age—neither birthplace nor genetics need be determinative of who we will be or how long we will live. But the same advanced technologies that have the potential to free us from living or dying according to a fixed blueprint also foster the view

³³² See Harmon, *supra* note 22, at 7 (noting that one can avoid an undesirable result from the application of a general rule of law by changing the general rule of law rather than by fabricating a legal fiction).

³³³ See *Ferrell v. Rosenbaum*, 691 A.2d 641, 651 (D.C. 1997).

³³⁴ For a thorough discussion of the constitutional objections to compelling children and mentally disabled adults to donate organs, which, to date, only the lower court in *Curran* has raised, see *Greatest Gift*, *supra* note 3, at 622-26.

³³⁵ See Dolgin, *supra* note 13, at 429; Robbenolt, *supra* note 10, at 229, 330.

³³⁶ See *McFall v. Shimp*, 10 Pa. D. & C.3d 90, 92 (1978); *In re Pescinski*, 226 N.W.2d 180, 183 (Wisc. 1975) (Day, J., dissenting); *supra* notes 115-17 and accompanying text.

³³⁷ See *supra* notes 56-90 and accompanying text.

that children and the mentally disabled are no more than the sum of their body parts. By holding out the elusive promise that death can be cheated and all disease checked, medical technology too often tempts parents and doctors to try to prolong life at all costs—even when it is a child or mentally disabled adult who ends up footing the bill.

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